DOCUMENT RESUME

ED 061 686 EC 041 774

AUTHOR	Springer, Ninfa Saturnino, Ed.
TITLE	Proceedings of the Conference on Nutrition and Mental Retardation (Ann Arbor, Michigan, February 10-11, 1971).
INSTITUTION	Michigan Univ., Ann Arbor. Inst. for the Study of Mental Retardation.
PUB DATE	71
NOTE	127p.
AVAILABLE FROM	University of Michigan, Publications Distribution Service, 615 East University, Ann Arbor, Michigan 48106 ($1.25)
EDRS PRICE	MF-$0.65 HC-$6.58
DESCRIPTORS	Biological Influences; Cognitive Development; *Dietetics; Eating Habits; *Exceptional Child Research; Manpower Needs; *Mentally Handicapped; *Nutrition

ABSTRACT

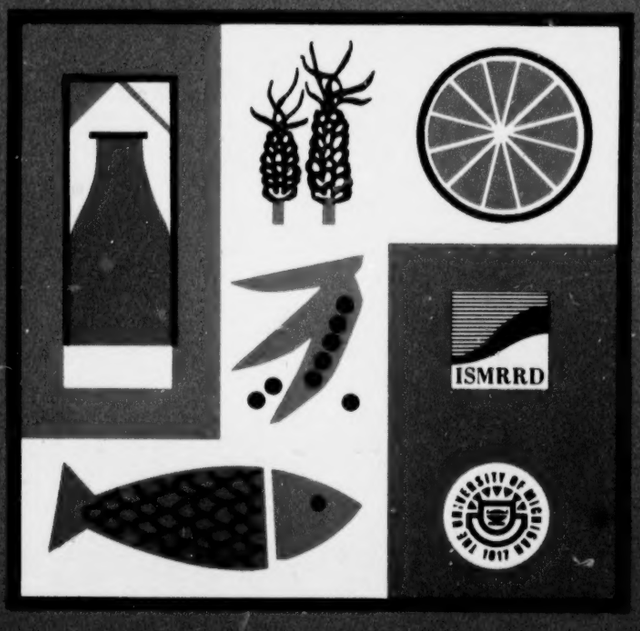
The conference, planned primarily for nutritionists and dieticians, dealt with the role of nutrition in the prevention and management of mental retardation. Proceedings include an overview of mental retardation, an examination of nutrition manpower needs in the fields of mental health and mental retardation on both the national and state levels, and a discussion of nutrition and learning in children that reviews studies on the effects of severe malnutrition on cognitive development. Dietary intervention in maple syrup urine disease and phenylketonuria is explained in detail. How to solve feeding problems of mentally retarded children is discussed by a nutritionist, occupational therapist, physical therapist, nurse, and speech pathologist. The final paper describes the role and activities of nutritionists in University Affiliated Centers. (KW)

ED 061686

Proceedings of a Conference on

NUTRITION AND MENTAL RETARDATION

Ninfa Saturnino Springer
Editor



Institute for the Study of Mental Retardation and
Related Disabilities, University of Michigan
Ann Arbor

EC 041744

Proceedings of the Conference on

NUTRITION AND MENTAL RETARDATION

Edited by

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615 E. University

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Price: $1.25

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PREFACE

The Institute for the Study of Mental Retardation and Related Disabilities is one of the University Affiliated Centers established throughout the United States with the primary responsibility of manpower development in the field of mental retardation. The Institute is the only one of its kind in the state of Michigan. Although its main responsibility is for training of personnel in the state, it has regional, national, and even international relationships with training and research centers and agencies concerned with the mentally retarded. The Institute has strong out-reach orientation and has cooperative ventures with state universities and colleges, state homes and training schools, and other community agencies.

The training program at the Institute utilizes the interdisciplinary approach. The Institute has brought together a faculty of varied interests and diversity in experience. The faculty represents the following disciplines: audiology, administration, child psychiatry, dentistry, nursing, nutrition, occupational therapy, pediatrics, physical therapy, psychology, social work, special education, and speech and language pathology. The program director for each discipline holds an academic appointment in his respective school in the University. Each program director is charged with the training of students, not only from his discipline, but from the other disciplines as well.

The training program at the Institute involves pre-service training for undergraduate and graduate students, in-service training for non-professionals, paraprofessionals and professionals already in the field of mental retardation and adult education programs for parents and other community groups.

In the initial development of the nutrition program at the Institute, the need for nutritionists and dietitians in the state was surveyed. The findings show that while very few have been exposed to the field of mental retardation, interest in this area is evident. Many of the nutritionists or dietitians employed in programs for the mentally retarded lack adequate training in this field. The acute shortage of nutrition manpower is even more marked in the out-patient clinics of state facilities and in other day training and activity centers which receive limited services from qualified nutritionists. A similar situation exists throughout the country. The shortage of manpower in nutrition does not necessarily indicate a lack of interest on the part of these professionals in the problems of mental retardation. The wide gap between demand and supply is a result of the lag in development of training programs in nutrition and mental retardation.

One of the priorities of the nutrition program at the Institute was the Conference on Nutrition and Mental Retardation held on February 10 and 11, 1971. Planned primarily for nutritionists and diet-

itians, the objectives of the Conference were to provide an overview of mental retardation and to present the role of nutrition in the areas of prevention and management. The importance of the role of nutrition in these areas is steadily gaining recognition. Proper and adequate nutrition during fetal and early post-natal life have been shown to be essential to the normal physical and mental development of the child. The prevention by dietary means of mental retardation in children with inborn errors of metabolism has repeatedly been demonstrated. The development and implementation of the methodology of feeding techniques by nutritionists, physical and occupational therapists and other health personnel represent an area of great potential in improving both home and institutional care of the retarded child.

The Conference, with a registration of 280 participants, was a success as judged from the evaluation forms. The number of participants attending is evidence of the great interest in nutrition and its interrelationship to the problems of mental retardation. The Conference was sponsored by the Institute for the Study of Mental Retardation and Related Disabilities in cooperation with the University of Michigan Extension Service, the Ann Arbor Dietetic Association, the Detroit Dietetic Association, and the Plymouth State Home and Training School.

The presentations of Drs. Cravioto and Waisman are available on video tape. Especially valuable is the video tape of the feeding demonstration which, unfortunately, cannot be included in these proceedings. Copies of these tapes are available at cost by writing to the Institute for the Study of Mental Retardation and Related Disabilities, 611 Church Street, Ann Arbor, Michigan 48104.

The Conference was supported in part by Project Number 923 from Maternal and Child Health Services, United States Department of Health, Education, and Welfare. The publication of these proceedings was made possible by McNamara Community Hospital of Warren, David Nursing Home, and Grand Packing Company.

Ninfa Saturnino Springer
February, 1972

MENTAL RETARDATION: AN OVERVIEW

William M. Cruickshank*

I am going to be talking with you around what I term a global definition of mental retardation, and try to see what the dimensions of this problem are. Though I am not a nutritionist, I will attempt to point out those places where nutrition and dietetics fit in, coincide, or interface. I suspect, technically, we could say mental retardation is a long-term, non-fatal, non-curable disease. I use the term disease because specifically and technically the word means "deviation" and as such what I just said is true. The problem of mental retardation is not popularly conceived of in this sense. From the jargon we use in lay and professional publications, we refer to it as a "condition." Nevertheless, it is a non-fatal, long-term, non-curable deviation in the growth and development of human beings. It affects all levels of the socio-economic structure of our society; none are free from this issue. Some groups within our structure are more liable to the problem than others, but this is not necessarily a matter indigenous to these groups. Rather it is a reflection of the unsatisfactory environmental and nutritional life which often surrounds them. Suffice to say that we are conceptualizing a problem which faces families of vice-presidents, governors, senators, representatives, physicians, lawyers, school teachers, grocery store and gas station owners, and families of individuals functioning at semi-skilled or unskilled jobs in our society. This is a respector of no socio-economic level; it is a respector of no person. It is a problem which in its gross number and magnitude is increasing. It is a problem where the percentage increase prevalent in the population is slightly on the rise, but relatively stable in terms of traditional

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notions about mental retardation. As we think of a more global definition of retardation, about which I wish to speak this morning and on which the Institute for the Study of Mental Retardation and Related Disabilities bases its program, we will see the magnitude of the issue being significant.

I would like to approach the problem this morning on the assumption that some of you are not familiar with this problem and perhaps are approaching it for the first time in a relatively structured fashion. I would like us to think of mental retardation as a paradigm, and we can do this if we envision the matter as a large cube (Figure 1).

We will deal with a three sided cube made up of a series of small interrelated cubes. Mental retardation will become very quickly, as a result of this paradigm, a very complex issue with which we must deal. We will begin briefly with traditional notions of mental retardation with which you may be familiar, and we will think first of the structure from the viewpoint of intelligence levels themselves. If we talk of "intelligence quotient" levels we envision various degrees of intellectual functioning from children at the bottom of the scale with almost unmeasurable intelligence quotients up to perhaps an IQ of 25 which is defined as profound retardation. In this state the residential care facility at Gaylord is particularly concerned with this group of children, although each residential care facility in Michigan has some of these youngsters. The profoundly retarded rarely become a community responsibility; that is, they seldom appear in day care centers.

The next group, as we move up the line, quickly becomes the responsibility of the community as well as the residential care facilities. This group of children arbitrarily fall into a category of intelligence between 25 and 40, and in Michigan they are referred to as severely retarded. These definitions vary slightly from state to state, but we will talk about our own program.

Moving up again we come to the group of youngsters with an IQ range from approximately 40 to 60 which gets us into the population that we call trainable. We definitely have these children in the com-

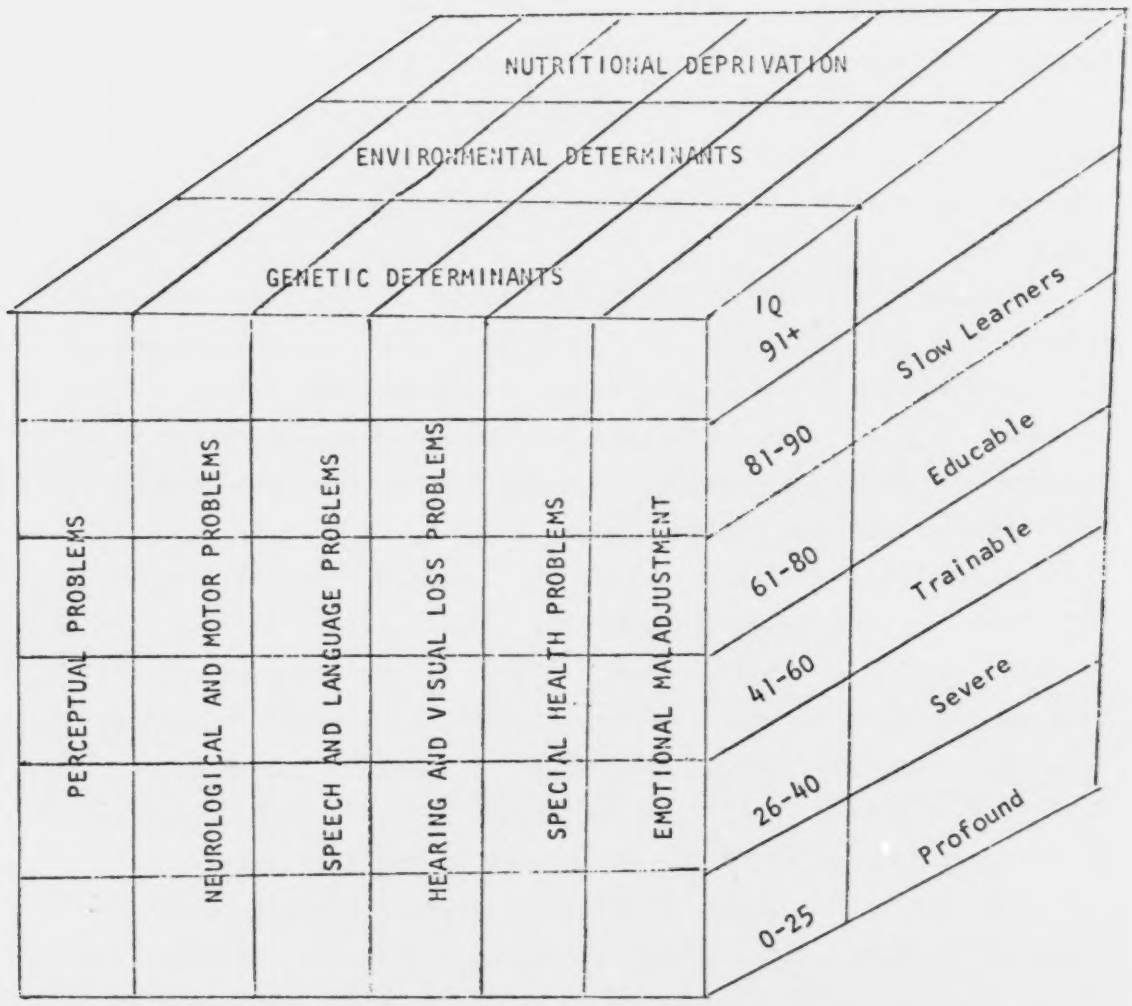
NUTRITIONAL DEPRIVATION
ENVIRONMENTAL DETERMINANTS
GENETIC DETERMINANTS
PERCEPTUAL PROBLEMS
NEUROLOGICAL AND MOTOR PROBLEMS
SPEECH AND LANGUAGE PROBLEMS
HEARING AND VISUAL LOSS PROBLEMS
SPECIAL HEALTH PROBLEMS
EMOTIONAL MALADJUSTMENT
IQ
91+
81-90
61-80
41-60
26-40
0-25
Slow Learners
Educable
Trainable
Severe
Profound

FIGURE I

munity as well as in residential care facilities. In this state they become the responsibility of the intermediate school districts and such facilities as the Sullivan School in Ann Arbor operated by the Washtenaw Intermediate School District, the Beekman facility in Ingham County, and facilities of this nature in Wayne County and elsewhere catering to trainable children who can, as the label indicates, receive and profit from self-help care training in a very marked degree.

We move still further in our paradigm to children whose intelligence quotient runs from the 60's to the 80's and without any question these are a public education responsibility. These educable children are children with retarded mentai development but who, as adults, will fill a tremendous occupational role in the community if the schools have been honest in the kinds of curricula and programs that are offered for them. These are children who fill hundreds of positions in hospitals, restaurants, automotive factories, and food service facilities of all kinds. These are the people who fill the semi-skilled and low-skilled jobs in most industries indigenous to a locality. They will vote, get driver's licenses, and many of these will marry and have their own children. You can immediately see the broad-based type of education which must be provided for them.

The next group which overlaps several other categories is the group of children with intelligence quotients in the 80's and low 90's. Categorized as slow-learning children they are, nevertheless, youngsters with some kind of retarded mental development. I am not saying mentally retarded now or mental deficiency, but they do function somewhat below norm. I want to include here in this definition of mental retardation the group of children with intelligence quotients above 90. Under certain circumstances even these children will function as retarded persons, but we will come to this in a moment as we consider some other aspects of our paradigm.

Thus far we have the structure that we have seen being used in the field of mental retardation historically since the early 1800's and before in this country. It is a classification that was in a sense imposed on us in the early work of Binet about 1805, and later

by Goddard and others of that era who were significant in the historical development of this field. It is one that has been adopted in varying forms by schools and agencies throughout the country, and, indeed, throughout the world. It has its limitations because it is concerned with only a single dimension, and mental retardation is much more than a single dimension.

I would like to look at another dimension of mental retardation: the determinants of mental retardation. These do have a very direct impact on the kinds of things we are going to be talking and thinking about during this conference. One great area in the field of mental retardation may be referred to as "genetic determinants" of mental retardation. This is an area in which people in the field of nutrition and the area of cytogenetics have direct impact. It is interesting to note that mental retardation is not necessarily as much a problem of genetic, familial, or hereditary recessive characteristics as we used to think it was. It is still a major issue, but it is not probably the most significant issue, nor is there any conclusive evidence linking the genetic factor to ethnic, racial, or socio-economic factors insofar as we understand it.

Other factors having significant impact on the way individuals utilize their capacity are such things as environmental determinants. This brings us to another significant aspect of our culture. I spent considerable time several years ago in the Andes of Peru working out of Cusco which is in the old Inca country. Cusco was the capital of the Inca empire. I was asked to go there because of the incidence of mental retardation in that area. This was not because there had been genetic strains of mental retardation, but because of the environmental deprivation which was obvious there. Practically no environmental stimulation whatsoever came into the lives of the very young infants of that culture. We see this happening in some of our very severe poverty pockets in the United States, specifically the center city issues and Appalachia.

In Michigan many are concerned with increasing intellectual apathy as an increasing amount of learning problems are beginning to be observed, in a very functional way, in the Keewenaw Peninsula, for

example. Iron mines have closed and parents have become tense and in a sense apathetic, and few resources are being brought to bear on the intellectual lives of their children. Within a matter of a few years rather marked changes have been noticed in the affect of these children. We certainly are aware of the issue as related to deprived segments of our center city problem. We have known about this issue and the impact of environmental deprivation which involves the interchange between human beings since the early work of Marie Skodack, Lester Dye, and Harold Skeels. Their work in the late 1930's indicated that if children failed to receive early infant stimulation before the age of two or three at the latest, mental retardation very likely would be established and that it was non-remissable in spite of the future stimulation after the chronological age of three. There is little question in my mind that the American society today is creating mentally retarded children in a most tragic way through the lack of adequate environmental interplay of children under the age of three. I am very much disturbed by the level at which the Head Start Program is pitched, for example. If the Head Start Program funds were utilized for children at the chronological age of four hours instead of four years, we would have a much different picture in the elementary schools as far as special education is concerned, in only a few years. This is an exceedingly important issue and one which adds a dimension to mental retardation that many professional people have not conceptualized or envisioned in the years just behind us.

A third dimension I will call nutritional deprivation, and this, too, is an issue which has an impact on the production of retardation on all levels. Data indicates that the impact of nutritional deprivation in the last two trimesters of pregnancy and during the first six months of post-natal life on the developing intellectual organism can be significant. Indeed, if nutritional deprivation continues during one or both of these stages non-remissable retardation may very well be a fact.

These are the three major issues among others on this plane of the paradigm. Now we have to conceptualize still other aspects which will be significant in terms of the way any of these factors inter-

relate with one another. For example, we are now aware of the impact of what I will call "perceptual problems" or maldevelopment on the growing intellect. These children have visual, audio, and tactual motor problems, and in other ways have their learning disrupted by what we think to be a forced response to stimuli and the inability to translate stimuli appropriately into socially approved motor actions. This kind of perceptual problem affects children at all levels and gets more significant as we move down the IQ scale, but this is the reason I keep an IQ of 90 and above in the picture. For example, we are now working with a 13 year-old boy with an estimated intelligence level of 130 or above. This boy, with estimated superior intellectual ability, is a non-reader and a non-writer. He is completely non-functional, and the issue is essentially the inability to conceptualize that which he sees or hears into appropriate motor responses. As such he is functioning as a mentally retarded child with a severe intellectual deficit. This accounts for many children who also have measured intelligence in the more traditional retardation levels. This is the group that years ago was spoken of as the "exogenous" type of mentally retarded, but it is also typical of the youngsters at a much higher level.

Closely related to that type of problem are children who also show neurological and motor problems. Let us consider the issue of cerebral palsy. In this group are a number of children with epilepsy and other types of central nervous system disorders. The issue becomes very complicated now because studies indicate that more than 80 percent of athetoid type cerebral palsy, and almost the same number of spastic hemoplegiac type cerebral palsy children, also have the perceptual malfunctioning that we spoke of before. About 75 percent of all cerebral palsy children function intellectually below the IQ of 80. Thus, we begin to have a complex multi-handicapped problem revolving around mental retardation. Sometimes it is so complicated and so severe that it is difficult to figure out just which handle one should grab first. In addition, other factors having severe impact on mental retardation or, indeed, causing and creating it themselves are the issues of speech and language dysfunction, hearing loss, and

visual loss. We have several studies that indicate approximately 30 percent of blind children function as mentally retarded children at some level. This is not necessarily to say that blindness and mental retardation are synonymous. It may mean that the impact of sensory deprivation noted in vision and hearing may serve to depress whatever intellectual capacity the child has, and thus he functions as a mentally retarded child more frequently than other children. We might also add other types of special health problems and particularly the issue of emotional maladjustment where under prolonged periods of tension, we have children who are more restricted in terms of the freedom with which they use their intelligence.

We, at the Institute, define mental retardation as anything which may have an impact on the intellectual function of the child or any aspect of intellectual deficit which is significant in terms of the total adjustment of the child.

We could make this paradigm more complicated than we have at this point. There is on the back of the paradigm the issue of traditional medical-clinical categories with which the professions need to deal. These are usually lumped down in the lower segment of the paradigm. We are talking now about the relationship between mental retardation in mongolism, cretinism, hydrocephaly, microcephaly, oxycephaly, and other medical-clinical categories having an impact on the way various factors relate to one another in terms of conceptualizing the total problem. You can see that the complexity I have already indicated can be magnified in several dimensions. This is why the federal government some years ago began a very strong program which is reflected in the kind of facility that Dr. Waisman administers at the University of Wisconsin and the kind of facility that we have at the University of Michigan. This type of facility is now being represented in a variety of other states where there has been a demand on the part of our culture. We attack this complex problem of mental retardation from a broad interdisciplinary point of view. Speaking only for our own facility, since I am more intimately familiar with it, we are attempting to attack the whole problem "nutritionally" if you will.

We try to attack the problem from the points of view of dentists, nutritionists, and persons in fields related to mental retardation such as speech and language pathology, occupational therapy, psychology, social work, pediatrics, child psychiatry, nursing, administration, and epidemiology. These are viewpoints of disciplines significant in understanding the life problems of these children. Interestingly enough, in these centers we are not approaching these problems, at least not in our center, from a disciplinary orientation. Anything that we do in the Institute is from a multi- or interdisciplinary orientation. I am absolutely convinced, and I make my life plan along these lines as far as professional work is concerned, that this complex issue of retardation which affects every facet of human life and every level of our social structure, cannot further be conceptualized by any one field alone. It encompasses too many issues from physiology to social concerns. Mental retardation is an issue that nutritionists are going to have to work through in conjunction with occupational therapists, with pediatricians, dentists, nurses, and people in whatever realm nutrition can play a significant, unique, and fundamental role. I urge you as you are thinking about your own relationship to this and other kinds of problems in human development to broaden your perspectives and to attack this problem in concert with your colleagues from disciplines which you might not have had too much association.

NUTRITION MANPOWER NEEDS IN THE FIELDS OF MENTAL HEALTH AND MENTAL RETARDATION: THE NATIONAL SCENE

Margaret Phillips*

INTRODUCTION

I am very pleased to have this opportunity to represent the Maternal and Child Health Service at today's Nutrition Conference sponsored by the University of Michigan's Institute for the Study of Mental Retardation and Related Disabilities.

The concern of the Maternal and Child Health Service for the child who is mentally retarded dates back to 1912, when, as a part of the Children's Bureau, its responsibility was to "investigate and report on all matters pertaining to the welfare of children and child life." Some of the first studies of the Children's Bureau dealt with retarded children. The responsibilities of the Maternal and Child Health Service have expanded over the decades and now include financial and technical assistance to a variety of programs that relate to the needs of retarded children.

Included in these programs is a heavy emphasis on prevention by strengthening the generic health services delivered to mothers and children; by the reduction of the incidence of mental retardation through the Maternity and Infant Care Projects; by the screening of newborn infants for PKU and other metabolic disorders; by cytogenetic studies and counseling; and by early screening and corrective care. Evaluation, diagnosis and follow-up care for children suspected of being retarded are provided through a network of special clinical programs providing a comprehensive approach to the problem through a multi-disciplinary health service team. The training of personnel to

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*Ed.D., R.D., Therapeutic Nutrition Consultant, Department of Health, Education, and Welfare, Public Health Service, Health Services and Mental Health Administration

deliver these services on a variety of levels has likewise become a major focus of the Maternal and Child Health Service.

One of the newer and more innovative approaches to the training of professional personnel who are to deliver services to the mentally retarded has been the development of the University Affiliated Training Centers for Mental Retardation. They represent a coordinated partnership of a number of constituent agencies of the Department of Health, Education and Welfare, some of our leading universities such as your own and a great number of departments and schools within the universities. These programs are attempting to turn out health workers who are not only expert in the application of their own professional skill to the problem of mental retardation, but who have also achieved an understanding of the roles of a variety of other professions and have had the opportunity to work and interact with them toward meeting the range of needs that retarded children and their families have. The Maternal and Child Health Service is participating in this effort through the support of faculty, staff and trainees in the health service areas of the University Affiliated Centers. Your Institute is one of 18 such new center programs.

In discussing nutrition manpower to serve retarded children and their families, I would like to focus on:

1. the size of the population of retarded children,
2. the nature of the nutrition services needed to serve this population,
3. the manpower available, and
4. manpower needs.

NUMBERS OF MENTALLY RETARDED CHILDREN

It is estimated that there are about six million mentally retarded persons in the United States today. About 2,500,000[1] of these individuals are under 20 years old. We can expect that some 126,000 babies born this year will be regarded as retarded at some time in their lives.[2] Some of the children included in these figures have multiple handicaps, which further complicates efforts to provide services.

Worsening of national health problems such as malnutrition, or development of an epidemic of measles may materially increase these figures and place a further strain on our limited service resources for these individuals. For example, one million measles cases over the next four years could cost the United States economy $29,600,000 in lifetime care for the mentally retarded resulting from such an outbreak.[3] This is not to mention the heartache of the families.

NATURE OF NUTRITION SERVICES NEEDED

In order to discuss the nutrition manpower needs for care of the retarded and handicapped we must have an understanding of the nature of the nutritional services needed. The child's diet and nutritional status need to be evaluated not just once, but at periodic intervals. His self-feeding skills must be evaluated in relation to the stage of growth and development and he must be given assistance and encouragement to function at his maximum potential of independence. Just as for other groups in the population, an important aspect of nutritional care is dietary counseling and nutrition education of the child and his family. Plans for nutritional care as part of total health care need to be developed in conjunction with the other members of the health team. This supports the idea that we must function together and share from all the disciplines.

It is imperative that the nutritionist have an understanding of the role and function of other members of the health team and know how to communicate and work with them in developing comprehensive care plans for the retarded child. The unique contribution of the university-affiliated centers is the opportunity for students to learn in an interdisciplinary setting.

It is important to stress that the normal nutrition aspects of care are equally as important as the therapeutic aspects. I think this is one of the reasons I prefer to say my specialty is therapeutic nutrition. All too often dietary counseling is provided only for children who need a modified diet. In addition, there is a tendency to sometimes overlook evaluation of nutritional status if there is no specific pathology or physically handicapping condition.

There is a growing concern in the United States as well as in the developing countries about the possible effects of malnutrition on human growth and development--both physical and mental. Research teams are attempting to pinpoint the effects of degrees of malnutrition and the period of life when they occur on mental development. The effects of other interrelated factors such as heredity, poverty and lack of environmental stimulation in early childhood are also being explored. It now seems probable that at least one major cause of retardation could be dramatically diminished by assuring all Americans a basically adequate diet.[4]

One of our most urgent priorities in the prevention of mental retardation will be to make certain that an adequate supply of nutrients is available to the foetus and infant, especially during the early months of life.

Many women still do not have access to an adequate supply of food due to lack of income and other related socio-economic factors and furthermore, do not realize the significance of nutrition to their health or the health of their offspring.

The Committee on Maternal Nutrition of the National Academy of Sciences[5] recently recommended that nutrition education programs be provided as part of school and community health services and that persons responsible for food programs and policies give high priority to infants, children, adolescents and pregnant women.

To achieve these objectives more nutrition manpower is needed. At present there is a wide gap between the manpower available and the nutrition services which are needed to strengthen the preventive aspects of health programs. In order to reach young girls and women to prepare them for their child-bearing years and to reach them during pregnancy and lactation to assess dietary intake, food habits and institute necessary counseling, we need to increase the number of nutritional personnel in basic community health services. Someone said that it is hard to believe there is a shortage of nutrition personnel due to the goodly number present today, but across the country there is an acute shortage.

PRESENT NUTRITION MANPOWER AND MANPOWER NEEDS

What is the nutrition manpower available today? Let us look first at the total nutrition manpower available in state, county and local programs which provide nutrition services for mothers and children. Many of these positions are made possible by Title V of the Social Security Act which authorizes funds to help states extend and improve their services for mothers and children. The total number of positions at the various levels is about 500. This number covers the entire country.

In addition, nutritionists, dietitians and home economists are providing nutrition services in the Maternity and Infant Care and the Children and Youth Projects across the nation. The professional nutrition personnel in these total about 300.

In these programs the nutrition personnel have multiple responsibilities and the coordination of their services with special mental retardation programs s only one of them.

According to data collected in 1970 on the numbers of nutrition personnel working specifically in community mental retardation clinics and university-affiliated training centers, there were 72 positions for nutrition personnel among some 160 programs reporting; ten of these positions were vacant. Forty-nine of the positions were full-time and twenty-five were part-time. Two home economists were included in this total count.

The 100 or so clinics which were without nutrition personnel received some part-time consultation from the nutritionists of other agencies--namely, the state, county and local health department and, in some cases, the Maternity and Infant Care Projects and the Children and Youth Projects. In a few clinics a hospital dietitian provided limited service.

In the past few years considerable progress has been made in increasing the nutrition services available; however, from the above data it is obvious that additional nutrition personnel are needed to work in programs for the retarded and handicapped.

Clinics which rely upon staff from other agencies for consultation are often not able to provide more than token nutrition service except

to a few selected patients. Personnel from other agencies must give priority to the needs of their own programs and they may have little time left to devote to the clinic's needs. A comprehensive nutrition program for mentally retarded children and their families which includes a plan for diet evaluation and diet counseling at periodic intervals is likely to be out of the question. Nor will low-income families receive adequate counseling about food assistance programs.

Manpower studies report that shortages of qualified personnel exist in most health occupations in most communities across the nation. This fact makes us realize that although other health personnel, such as nurses, physicians, physical therapists, occupational therapists and social workers, are also concerned with the relationship of nutrition to health, the time they can devote to specific nutrition services may be limited by factors beyond their control. Moreover, they usually do not feel competent enough in this area to provide the in-depth dietary counseling needed. A study conducted by this author[6] in four medical schools revealed that this lack of confidence among physicians is due, to a great degree, to the fact that inadequate attention is given to nutrition in the curriculum.

Because of the scarcity of nutrition personnel, we often spread ourselves too thin, with the result that we are not able to demonstrate adequately our role and function to the other professions. We are not always available when needed to participate in staff conferences related to patient care or in staff education or to meet with other disciplines to develop treatment and care plans.

In addition to the nutritionists and dietitians who are working in community health service programs and clinics for the retarded and handicapped, there are also many involved with the nutritional and food service aspects of residential facilities and day care programs for the retarded. We do not want to give inadequate attention to this group. The same problem of scarcity of nutrition personnel exists in residential facilities as well as community programs. In a 1963[7] survey of state institutions for the mentally retarded it was found that almost one-third had no dietitian on the staff. This lack of professional dietetic staff resulted in inadequacies in meeting the

dietary needs of the patients. For example, there was little consistency in caloric value of foods provided the various age groups; six to twelve year olds were provided with as little as 1200 calories per day and as much as 4000 calories per day, regardless of their particular need. This is just one example of the things which are not really new to you.

So far our discussion has dealt mainly with the professional person. Any consideration of manpower should include all levels of workers--the technical and auxiliary worker, as well as the professional. There are food service workers, diet aides and the newest category in the nutrition field, the dietary technician.

The shortages of supportive personnel are also serious. Supportive workers are a crucial part of the manpower structure because they can be in closer contact with the patients. It is noteworthy that half of the state institutions in the 1963 survey reported that one of their major problems was a food service staff which was too small and undertrained and which had a high rate of turnover. So those three problems combined worsened the problem of services.

In order to assess present and future needs for nutrition manpower for the mentally retarded with some degree of accuracy, we should have a comprehensive system of data collection. We do know, however, that some budgeted positions remain unfilled. This may have some relation to the fact that in some areas of the country and in some agencies, the salaries for nutrition personnel are low; in addition, there is a lack of qualified candidates.

It sounds like we have a manpower problem, but this is an especially fascinating, exciting and challenging time for dietitians and nutritionists. With the increased awareness of the relationship of nutrition, poverty and environmental influence to health and mental development, with new legislation being passed, i.e., the Developmental Disabilities Act, with new programs developing that have a component of nutrition and nutrition education, there are increasing opportunities for significant contributions to health care. New facilities and equipment, new methods of data collection and processing and new philosophies of health care exert a continual modifying influence

on the functions of health professionals.

In an analysis of manpower needs it is imperative to examine and delineate the role, the functions, both general and specific, of each person on the discipline's spectrum of personnel--from the professional to the auxiliary worker. What should the nutritionist do? What tasks can the technician perform? How are these interrelated? What kind of organizational pattern can be established to insure maximum communication, in-service education and on-going supervision? Furthermore, how can we develop a continuum in the preparation, utilization and advancement of the different types of professional and auxiliary workers in the field of nutrition? The development of this continuum is terribly important as we try to give adequate care.

In answering all of these questions, the central objective of providing quality nutritional services for each child and his family must be kept in mind.

In summary, I would strongly recommend that in the area of manpower we look at these things and try to accomplish them:

1. nutrition personnel working or planning to work in programs for the retarded take advantage of graduate training opportunities provided by the university affiliated centers to develop understanding and experience in a multidisciplinary and an interdisciplinary approach to the care of the retarded.

2. more complete data on numbers of nutrition personnel at all levels in programs for the retarded and handicapped be collected.

3. that the manpower needed at different levels be determined.

4. that roles and functions of various levels of nutrition personnel be analyzed.

5. that tasks which may be delegated to the technical assistant and the auxiliary worker be determined.

6. that nutrition services be better coordinated. Some states are doing a good job in this area; others need to work harder.

7. that new ways of performing tasks, new methods of data

collection and new means of providing health services which may result in quality care for more people be considered.

In closing, I would like to quote the stated objective of the 1970 White House Conference on Children; it seems particularly significant for health personnel, such as ourselves, in programs for the retarded and handicapped.

"To enhance and cherish the individuality and identity of each child through recognition and encouragement of his or her own development, regardless of environmental conditions or circumstance of birth."

Thank you again for this opportunity to be with you. I hope to have the chance to talk with you today and tomorrow.

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NUTRITION MANPOWER NEEDS IN THE FIELDS OF MENTAL HEALTH AND MENTAL RETARDATION: ON THE STATE LEVEL

Armesia Lloyd*

We are going to talk about the Food Service Section of the Department of Mental Health, where very little has been done. It has taken quite some time to break the ice and have people in policy-making positions listen to some of our questions, suggestions and directions. Most concern has been with the food dollar, with medications, and now with drugs. The current stress on drugs takes all interest away from everything else.

Very little has been done within the Food Service Department in nutrition. It has taken some ten years to get those involved in policy making positions to really become concerned with problems in providing staff and adequate service to the patients.

Ten years ago the Department of Mental Health had 16 agencies. Today there are twenty agencies in addition to programs on contractual basis. The patient population in 1960 was over 30,000; today the number is approximately 23,000. The trend is to rehabilitate, or place the patient into the community.

To direct the activities involved in feeding within the eighteen agencies are six registered dietitians; they are at Newberry, Plymouth, Pontiac, Traverse City, Lafayette Clinic and Hawthorne Center. Our plans are to provide experience to those interested in American Dietetic Association membership. In the meantime we plan to investigate the possibilities of affiliation with dietetic internships. Demands for health services are becoming greater. With increased advances in technology, trained employees on all levels become a necessity.

The Food Service Committee has (1) developed, implemented and

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evaluated cycle menus; (2) investigated and tested the practicality of prepared entrees; (3) the development of a computerized program for menu nutritional values, purchasing, food cost, etc; (4) plans for training programs for all involved in feeding.

Many individuals within the Department of Mental Health recognize the need for trained staff to head food facilities and will support programs involved in feeding the patients, but the final decision on staffing is left to each agency. By this I mean the agency makes the decision on whether it is necessary to provide a dietitian, no matter what the size of the institution might be. We have physical facilities to provide training and research in many areas related to nutrition. The possibilities of providing meaninfgul information is unlimited. This cannot be accomplished without trained staff.

Our staff have not projected themselves in the overall treatment of the patients; this has been a very big error. In few facilities will you find charting on a patient.

A six month review of institutionalized patients should be made, especially those having feeding difficulties and other problems. A day by day review in some cases should be noted.

We plan to provide training for all those directly involved in feeding at the agency, also providing consultation to day care and extended care facilities.

We look forward to making training available within the Department of Mental Health by adding competent staff to train others. The present heads of the Food Service Department are eager to participate in training programs at University Centers. The training of dietitians will be followed by training food service supervisors, attendants, etc.

I hope some of the dietitians present will become interested in employment in the Department of Mental Health. The salaries are not bad and the need is great.

Thank you.

NUTRITION AND LEARNING IN CHILDREN

Joaquin Cravioto*

Either singly, or most often in combination, malnutrition and infection are the main contributors to disease in preindustrial societies. Advances in the diagnosis and treatment of accompanying infections, and a more detailed knowledge of the biochemical pathology of malnutrition, together with a better knowledge of the differential homeostatic responses of malnourished and well-nourished children to various common noxa, have reduced the lethality due to malnutrition to such a low figure that concern with the fate of survivors has become a major research field both for the human and the experimentalist nutritionist.

Although concern with nutrition in child development is not new, and one of the basic concepts in child health has been that a diet adequate in quality and quantity is essential for optimal growth and development, it is only recently that systematic attention has been directed to the possibility that malnutrition in early life may contribute to suboptimal intellectual functioning and learning disabilities in later life.

This afternoon I will attempt to review some studies whose results show that survivors from severe malnutrition tend to perform on intellectual and learning tasks at a level below that corresponding to subjects of the same social class.

On a world-wide basis, the topic is important because from three to ten percent of all preschool children in almost two-thirds of the world suffer from severe malnutrition during the first years of life. It may be remembered that in preindustrial countries close to one-half of the total population is below 15 years of age, and usually twenty

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percent are children under 5 years of age.

If one considers the size at birth of infants born in communities with a high prevalence of severe infantile malnutrition, it becomes evident that in comparison to newborns from industrial societies, they are lighter in weight and shorter in length. Figure 1 illustrates the distribution of birth weight in the total number of children who were born in a typical preindustrial village in Central Mexico during one calendar year. Out of a total of 291, there were 8 infants weighing 1500 to 1999 gms, 28 weighing 2000 to 2499 gms, 147 with weights between 2500 and 2999 gms, 86 weighing 3000 to 3499 gms, and 22 weighing 3500 to 3999 gms. Mean birth weight was 2898 $\pm$ 444 gms. It may be seen that 12.4 percent of newborn infants had birth weights below 2500 gms, whereas only 7.6 percent of the cohort weighed more than 3500 gms. The mean birth weight and the weight distribution closely resemble the figures reported for Indian infants in Dehli, Negro infants of the French Sudan, and Indian infants from Singapore. The mean birth weight is significantly below that of Scandinavian and North American newborn infants.

Total body length at birth is represented in Figure 2. The median for the total birth cohort was 48.5 cms, with twenty-five percent of the infants between 44 and 47 cms, and twenty-five percent between 49.5 and 53 cms. Boys had a mean length of 48.7 $\pm$ 1.8 cms, and girls 48 $\pm$ 2.0 cms. The proportion of weight to length at birth was normal in all cases.

The longitudinal study of this community has provided evidence that size at birth is not a good predictor of risk of subsequent development of severe clinical malnutrition. Size at birth is unrelated both to the occurrence of severe clinical malnutrition and to the age at which such severe malnutrition occurs. These findings lead to the suggestion that the factors which influence intrauterine size may be quite different from those which influence nutrition and growth in the postnatal period.

The level of motor competence at birth is presented in Figure 3. The values were calculated from those items of the Gesell motor scale for which alternatives at the age of 4 weeks or later were possible. Median ability was equivalent to 12 days. Twenty-five percent of the

Figure 1

BIRTH WEIGHT OF CHILDREN IN THE ANNUAL COHORT OF BIRTHS

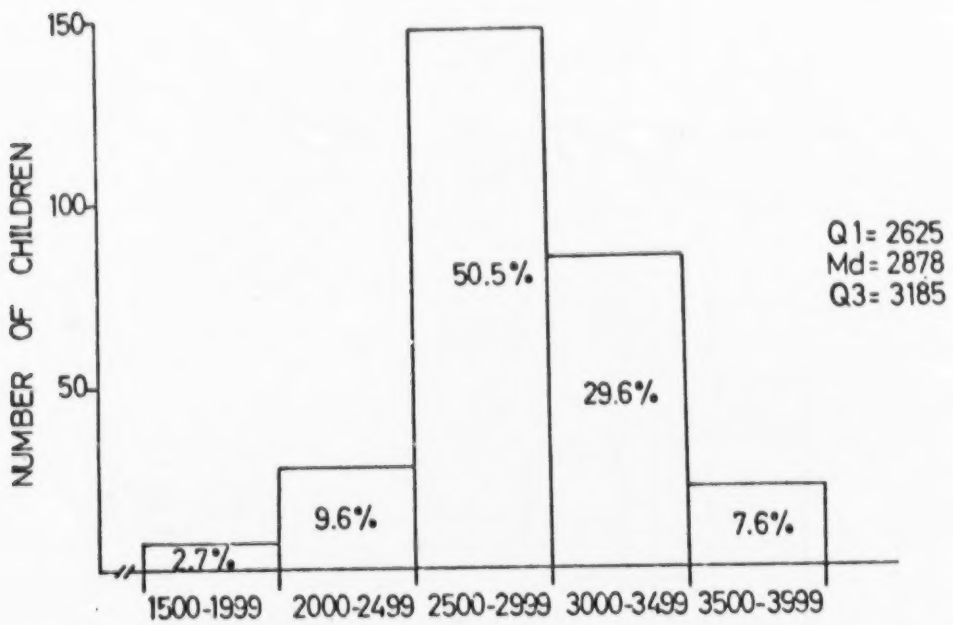


Figure 2

DISTRIBUTION OF TOTAL BODY LENGTH AT BIRTH IN COHORT

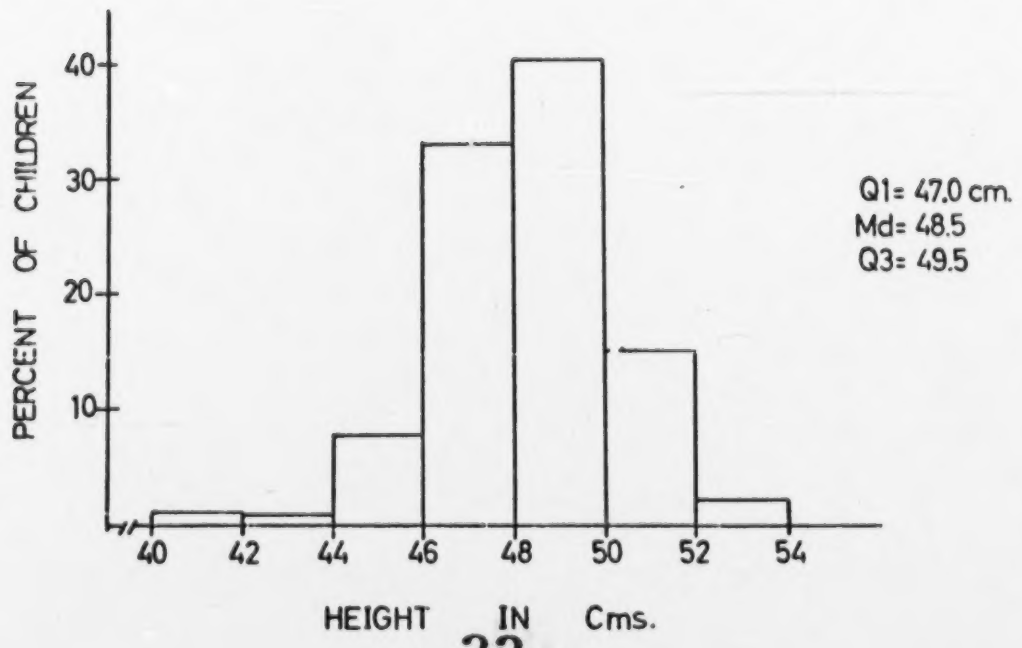
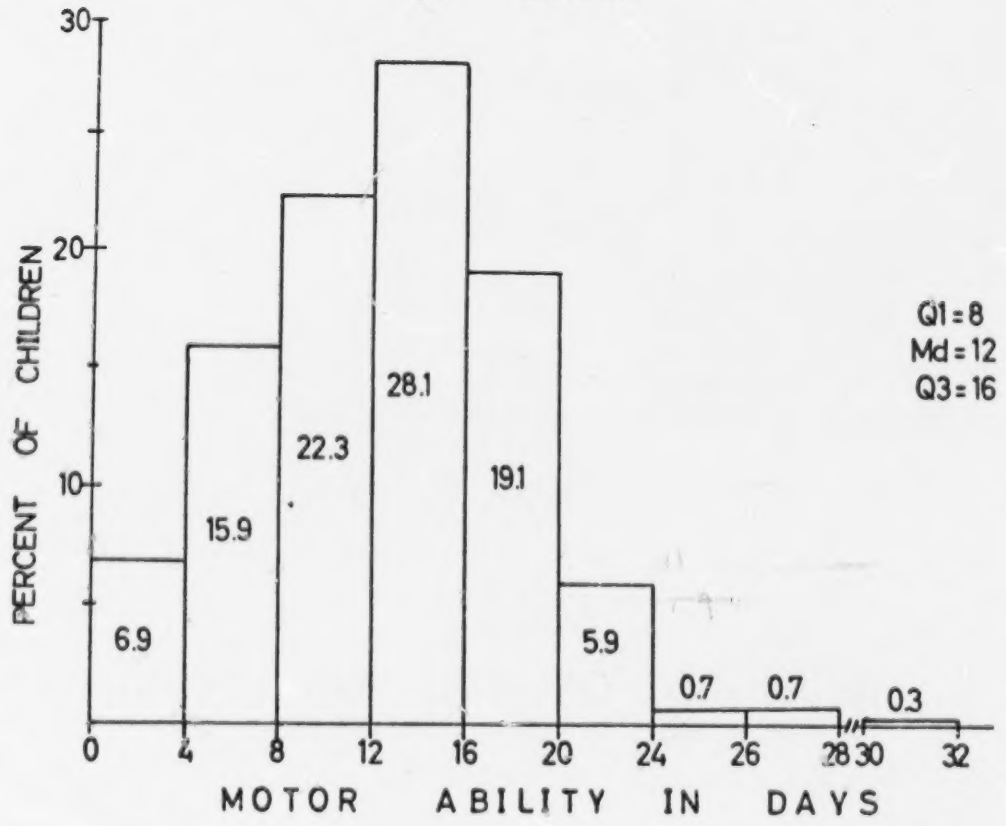


Figure 3

MOTOR ABILITY AT BIRTH IN COHORT



children had scores between 4 and 8 days, and twenty-five percent of the infants showing performance equivalent to 16 days or more. Precocity in motor organization has been reported in newborn infants from several preindustrial societies in Central America and Africa. The level of motor competence at birth permits us to state that neurological organization at the beginning of postnatal life is at least normal even in children who later on become severely malnourished.

Studies of somatic growth of children living in communities where protein malnutrition is highly prevalent have shown that even those children who develop severe clinical forms of malnutrition have generally grown well during the first 3 to 6 months of their lives when breast feeding provides adequate nourishment. Later, because suitable supplements are not added when mother's milk cannot by itself supply all the infant's requirements, growth begins to be retarded. If the infant is then subjected to the added stress of an infection, he either dies or goes through several tortuous months of partial recovery and reincidence until he finally improves his competitive position for food in the family and the family prejudices about his food and feeding changes so more of the available foods are considered adequate for him. By this time too, because of his smaller dimensions, his food requirements are lower and his chances of a more or less adequate intake for his size are also increasing, giving him a better opportunity for survival.

Adequate nutrition is crucial for optimal growth, but in dealing with mental development, food and feeding become something more than nutrients. Within this context, food should be viewed at least in three complementary dimensions.

FOOD AND FEEDING

1st Dimension:	Physiologic
Unit:	Nutrient
Objective:	Provide Chemicals to Body
2nd Dimension:	Psychophysic
Unit:	Foodstuff
Objective:	Provide stimulation through consistency, color, temperature, aroma, flavor, etc.

3rd Dimension;	Psychosocial
Unit:	Meal
Objective:	Symbol system. Practice and demonstration of clear role of status.

The first one, which may be called the physiological dimension, has a unit of measurement, the nutrient (and calorie) and its function is the provision of chemical substances for growth, maintenance, and regulation. The second food dimension may be termed psychophysical. Its unit of measurement would be the foodstuff which through its organoleptic properties would provide the child with a variety of stimuli (consistency, color, aroma, temperature, taste, etc.). Within the context of this dimension, the same foodstuff presented at the table in the form of two different kitchen preparations having the same nutrient content will in fact behave as if there were two different foods. Finally, the third dimension of food is of a psychosocial nature. Its unit of measurement is the mealtime. Its functions are on the one hand to aid in symbol formation through the social value attached to it, for example as a means of reward or punishment; as an experience link to a gratifying or not gratifying person; as a characteristic of the ethnic group of the social group to which the family belongs or desired to belong, etc. On the other hand, the mealtime provides opportunities to demonstrate and practice role and status at the family and at the community level. Who is waited on first? Who sits at the place of honor at the table? Who receives the best part of a dish? Who moderates conversation at the table? Who can break, without consequences, the rules and manners at the table? These are some examples of some of the expressions of this food dimension.

It is apparent, given all these properties of food and feeding, that if a small child does not receive adequate food, there always is the possibility of having, besides a shortage of nutrients, less opportunity for stimulation and less opportunity for adequate socialization.

In the early 50's, there was very little interest in the study of

the relationship between nutrition and mental development. The repeated observation that infants and children at a high risk of malnutrition tend to cluster in the lowest social and economic segment of the population plus the fact that these segments tend also to have poorer housing, higher morbidity, lower levels of educational achievement, greater degrees of attachment to traditional patterns of child care, and in general to live in circumstances which are less conductive for the development of technologic and educational competence, led scientists to believe that the effect of malnutrition was just the effect of social class, not deserving a separate investigation.

Pediatricians and nutritionists had repeatedly observed that apathy was one of the most constant signs present in severely malnourished children. From the very first description of protein calorie malnutrition, it was clear that psychological disturbance was a prominent feature of the syndrome. The severely ill, malnourished patient seems to have lost the curiosity and desire for exploration that characterizes the normal preschool child. This condition of unresponsiveness is so marked that renewal of interest in the environment is considered as one of the most reliable symptoms of improvement.

However, since that behavior can be present as a result of emotional deprivation, it was considered inadequate to view the observed apathy as a direct result of malnutrition. Moreover, since in a high proportion of cases, malnutrition is closely associated in time with weaning, a period of life accompanied in many preindustrial societies by the frequent absence of effective and continued mothering as reflected in the absence of a stable surrogate, it was thought that this emotional loss could also play a part in the causation of apathy.

Therefore, although it was accepted that during the development of chronic malnutrition from the mild moderate to the severe case, failure to respond appropriately to significant stimuli, as reflected in a progressive withdrawal from the environment and by a progressive behavioral regression, was a common feature of severe malnutrition, it was not considered worthwhile to study the separate effect that the nutritional variable might have on its production.

The work of Keys and associates published in 1950 demonstrated

that malnutrition affects psychological performance but it does so in a transient way. By subjecting normal voluntary adults to severe food restriction these investigators found that when the adults had reduced their body weight to figures representing seventy to eighty percent of their normal weight their mental performance on a varity of tests was frankly impaired. During rehabilitation, performance improved and by the time the subjects were considered as recovered from malnutrition, their scores were classified as normal.

In the discipline of pediatrics, we are accustomed to think that results obtained in adult subjects and in older children are not always applicable to fast-growing organisms. Since available data both in human infants and in experimental animals was consistent with the idea that severe protein-calorie malnutrition affects the normal pattern of biochemical maturation, it was considered as improbable that the central nervous system could not participate in this general deceleration of growth and development. Accordingly, it was hypothesized that the effect of malnutrition on mental development would vary as a function of the period of life at which malnutrition would be experienced.

To test the hypothesis, all severely malnourished children admitted to the nutrition ward of the Hospital Infantil de Mexico during the year 1959 were selected for study.

Immediately after treatment of any infectious disease and correction of electrolyte disturbance, the behavior of the children was assessed by means of the Gesell method. Tests were repeated at regular intervals of two weeks during the entire period that the children were hospitalized. In all, serial information was obtained on 20 children: 6 infants below 6 months of age, 9 between 15 and 29 months, and 5 between the ages of 37 and 42 months.

The results of the first test session confirmed previous reports, since all children were noted to have below age-norm scores in all fields of behavior. As recovery from malnutrition occurred, developmental quotients increased in most of the patients and the gap between normal age expectation and the actual performance of the child progressively diminished for all except those in the group whose age on

admission was less than six months. These younger malnourished infants showed no tendency to "catch up" and increased in developmental age only by a figure equal to the number of months they remained in the hospital. In older children, not all spheres of behavior exhibited the same speed of recovery. Language, which in general was the function most affected, showed the slowest rate of return toward normal age expectancy. When the serial data for each child were plotted against days of hospitalization, it could be seen that the rate of behavioral recovery from the initial deficit varied in direct relation to chronological age at admission. The older the group, the greater the value of the slope. The slopes were sufficiently steep, and progress in the first two weeks of treatment was so rapid that it appeared unlikely that the differences between initial test performance and level of functioning at the end of treatment could be due solely to the extra care and attention that the children had received in the hospital. Figures 4 and 5 illustrate the difference in recovery as a function of age on admission.

If intelligence is understood as the ability to cope and adapt to new circumstances of life, and is reflected in the increasing complexity of the channels through which the child acts on objects, the adaptive sphere of development as explored by the Gesell method is probably the area of behavior that can best serve in the small child as an analogue for later intelligence. In this context, the persistence of low scores in adaptive behavior found in infants who had suffered protein-calorie malnutrition before the age of six months suggests more than a transient loss in intellectual capacity. It is possibly indicative of a potential reduction in functional level in later years. In older groups of infants it is possible that the lag in adaptive functioning is a transient phenomenon and that the initial deficit will tend to be overcome if other relevant factors do not interfere.

The findings of an association between severe malnutrition and lags in mental development is in no way an actual demonstration of causal relationship between the two conditions. The association nevertheless pointed out the importance of studying the problem in a

Figure 4

RELATION BETWEEN DAYS OF HOSPITALIZATION AND EVOLUTION OF ADAPTIVE DEVELOPMENT IN CHILDREN RECOVERED FROM ADVANCED MALNUTRITION
(Group 15-29 months of age)

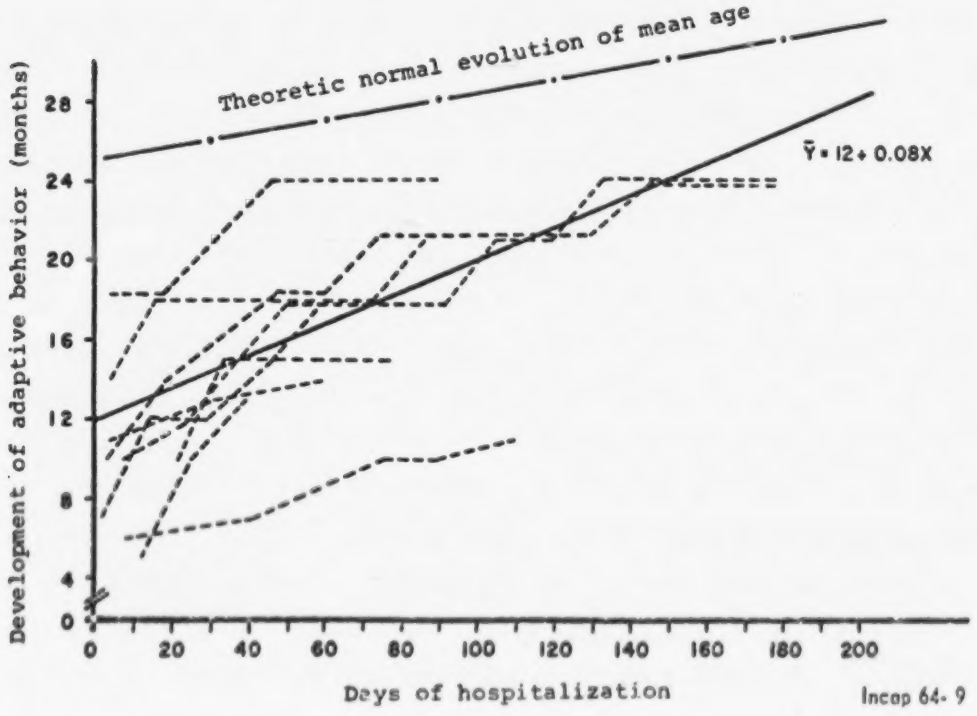
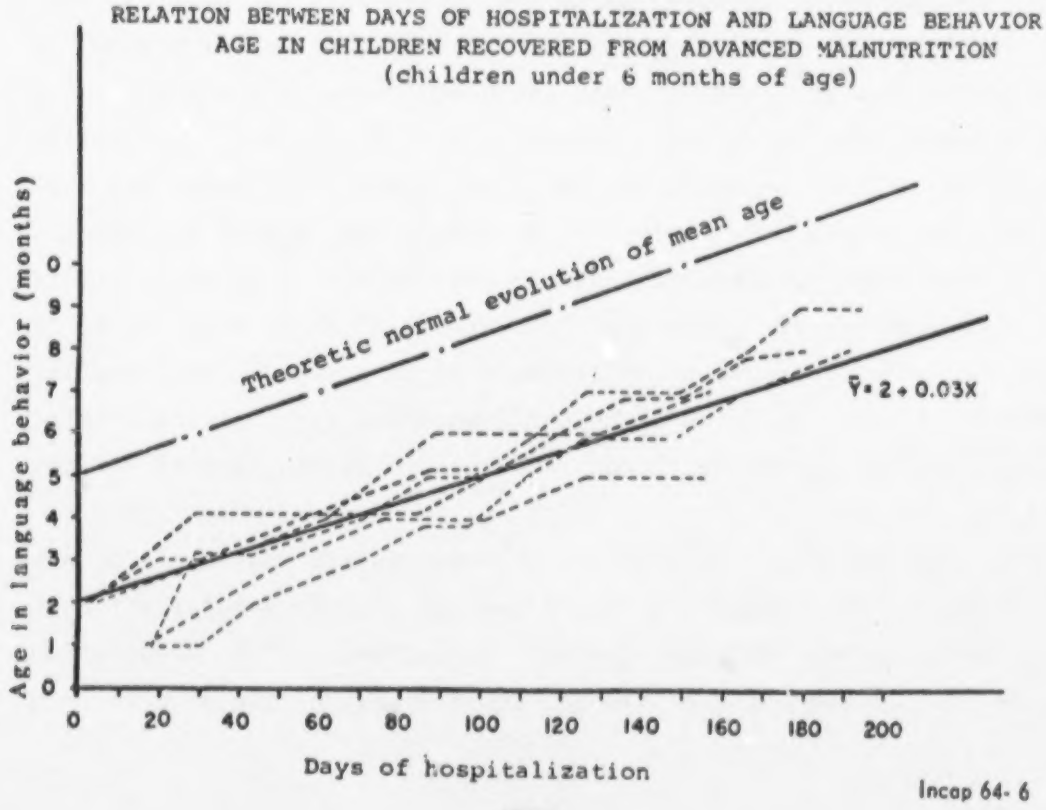


Figure 5

RELATION BETWEEN DAYS OF HOSPITALIZATION AND LANGUAGE BEHAVIOR AGE IN CHILDREN RECOVERED FROM ADVANCED MALNUTRITION
(children under 6 months of age)



more systematic manner through a longitudinal study.

Since in a longitudinal study a long time must elapse before the required data are obtained, we have been attempting in the interim period while collecting the relevant data, to explore certain meaningful issues through a series of cross-sectional studies of children who suffered severe malnutrition early in life, and of school-age children at a high risk of having had severe malnutrition during their preschool years of life.

In these associative cross-sectional studies, research has been oriented to answer the practical question of whether the more readily noted reduction in somatic growth and biochemical lags found in severely malnourished children are associated with reduced mental development, and if mental lags are present whether they represent permanent changes in functional effectiveness or are merely transient phenomena which disappear with nutritional recovery.

On this occasion I would like to discuss the results of the study carried out on a group of school-age children who had suffered severe malnutrition before their thirtieth months of age. The children were selected from the records of those who had been admitted for severe mainutrition with edema and skin lesions (kwashiorkor) to the Department of Pediatrics, Army Central Hospital in Mexico City between the years of 1952 and 1963. Their ages at the time of admission to the ward were between 4 and 30 months. At this time, they had weights forty percent or more below the mean expected weight for age. Children suffering from chronic disease, either infectious or not infectious, as well as children affected with diseases of the central nervous system, were eliminated. Due to limitations of staff and financial resources, only children living in Mexico City were considered as candidates for the investigation. With these restrictions, it was possible to locate thirty-nine children.

Since it is a well-known fact that the environment in which these children live is so grossly inadequate, it was decided to include as a comparison group a sample of the living siblings in an attempt to diminish the effect of this variable on the results. Accordingly, in each family the sibling closest in age to the previously malnourished child was selected for inclusion in the comparison group.

The level of intelligence was assessed by a trained psychologist by means of the Weschler Intelligence Scale for Children (WISC) in

both the verbal and the performance aspects. Auditory-Visual Integration was evaluated by the technique of Birch and Belmont and the level of Visual-Kinesthetic competence was explored by the technique of equivalence in the perception of geometric forms, as devised by Birch and Lefford.

As can be seen in Figure 6, the distribution of intelligence scores is markedly skewed with a large number of subjects scoring in the lower range of values. When the respective performance of the siblings and the malnourished groups are compared, it becomes evident that the children who were severely malnourished are significantly overrepresented in the lower extreme of the distribution.

If the verbal and performance scales of the intelligence test are analyzed separately (Figures 7 and 8), it may be noticed that significantly lower scores are attained by the previously malnourished children in tasks requiring verbal elements as well as in tasks demanding non-verbal responses. The difference of mean scores calculated by the "t" test is significant at the 0.01 level of confidence.

Figure 9 shows the mean performance of previously malnourished children and their siblings in a test which requires the child to identify visual dot patterns corresponding to rhythmic auditory ones. As may be seen, the children's ability to equate a temporally structured set of auditory stimuli with a spatially distributed set of visual ones is frankly inferior age by age in the group who had suffered severe malnutrition in infancy. To illustrate that this difference in performance is not due to a few extreme cases affecting the mean value, Figure 10 presents the cumulative percentage of seven year old children in the two groups. The data clearly indicate a lag in development of auditory-visual competence in children recovered from severe malnutrition.

The visual-kinesthetic intersensory integration, and ability closely related to learning to write, was explored by the method of equivalence in the perception of geometric forms. The kinesthetic sense, in this context, refers to the sensory inputs obtained through passive arm movement. Such motion entails sensory input from the wrists, elbow and shoulder joints and from the arm and shoulder muscu-

Figure 6

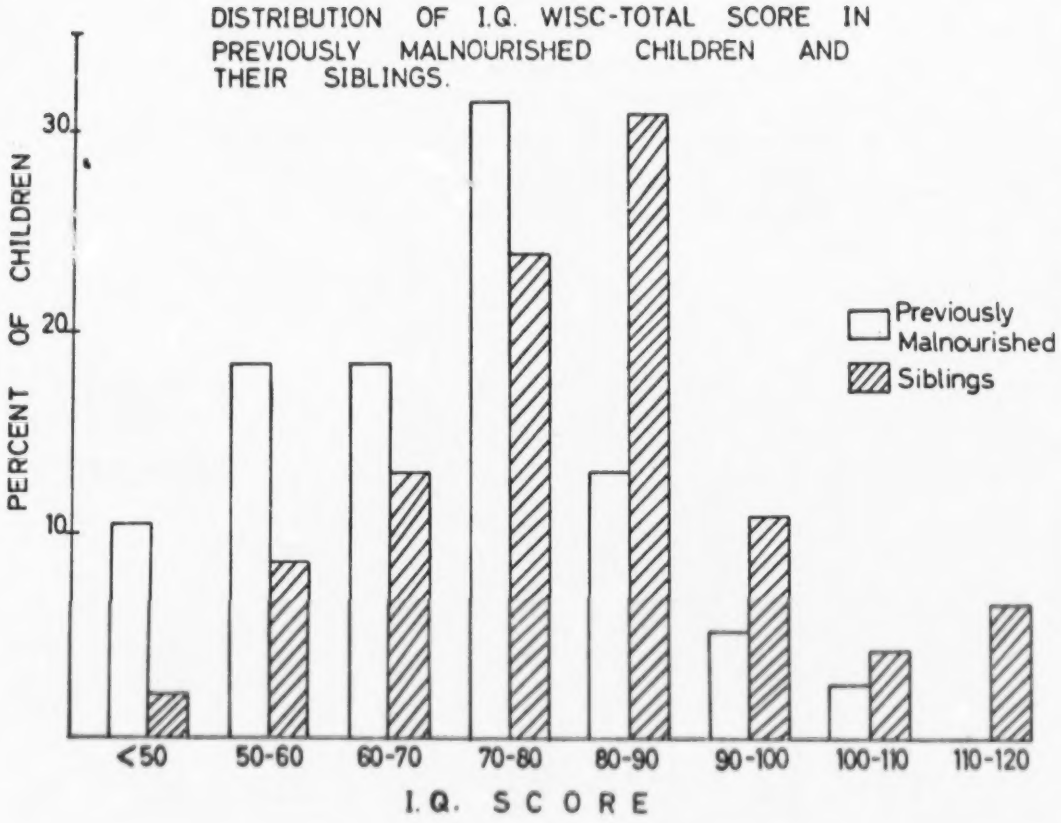


Figure 7

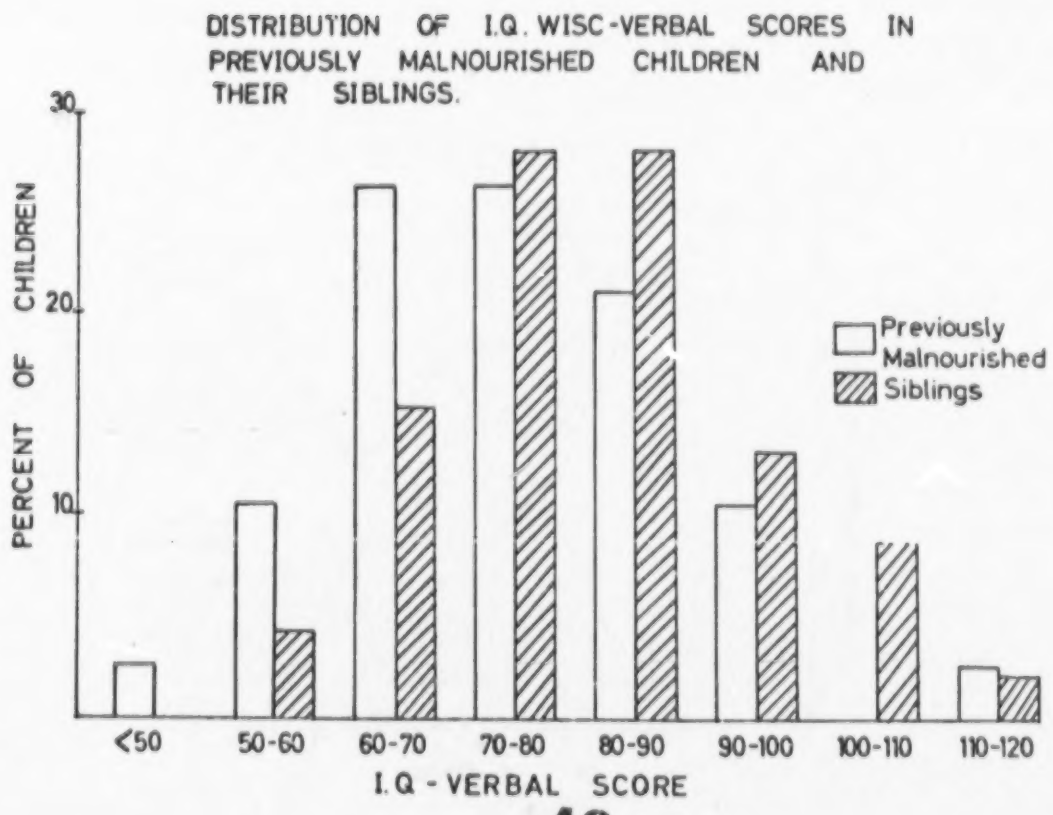


Figure 8

DISTRIBUTION OF I.Q.-WISC- PERFORMANCE SCORE IN PREVIOUSLY MALNOURISHED CHILDREN AND THEIR SIBLINGS.

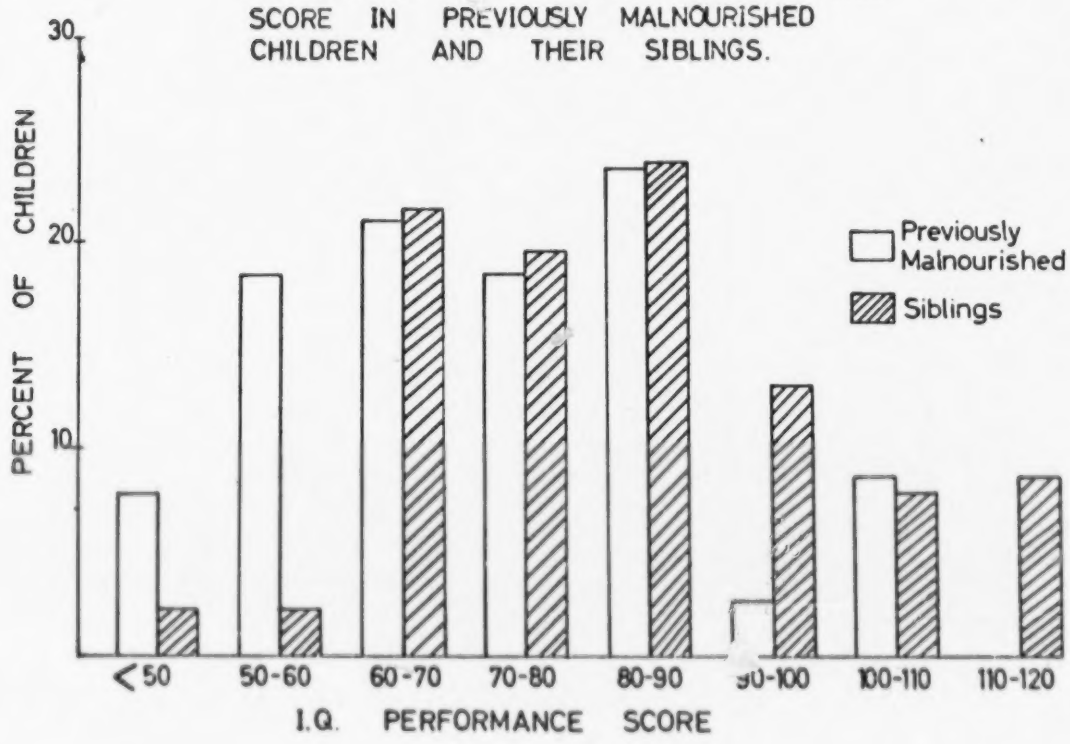


Figure 9

AUDITORY-VISUAL INTEGRATION IN PREVIOUSLY MALNOURISHED CHILDREN AND THEIR SIBLINGS

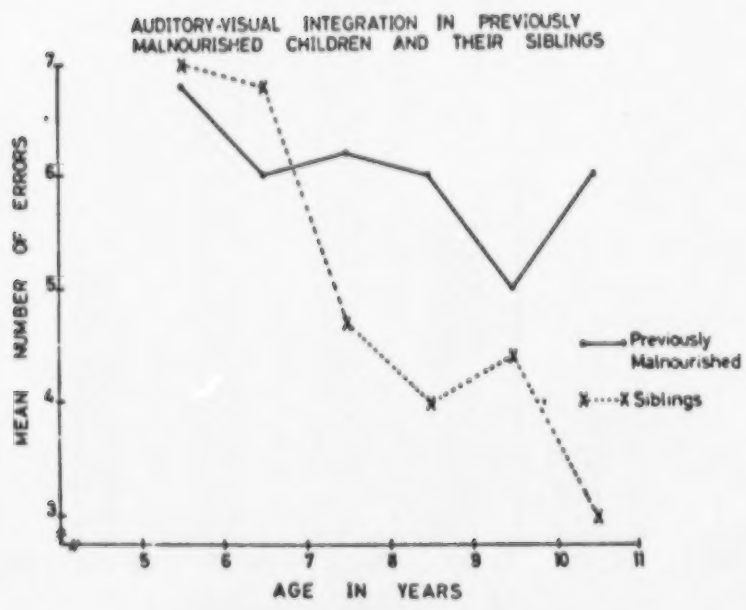
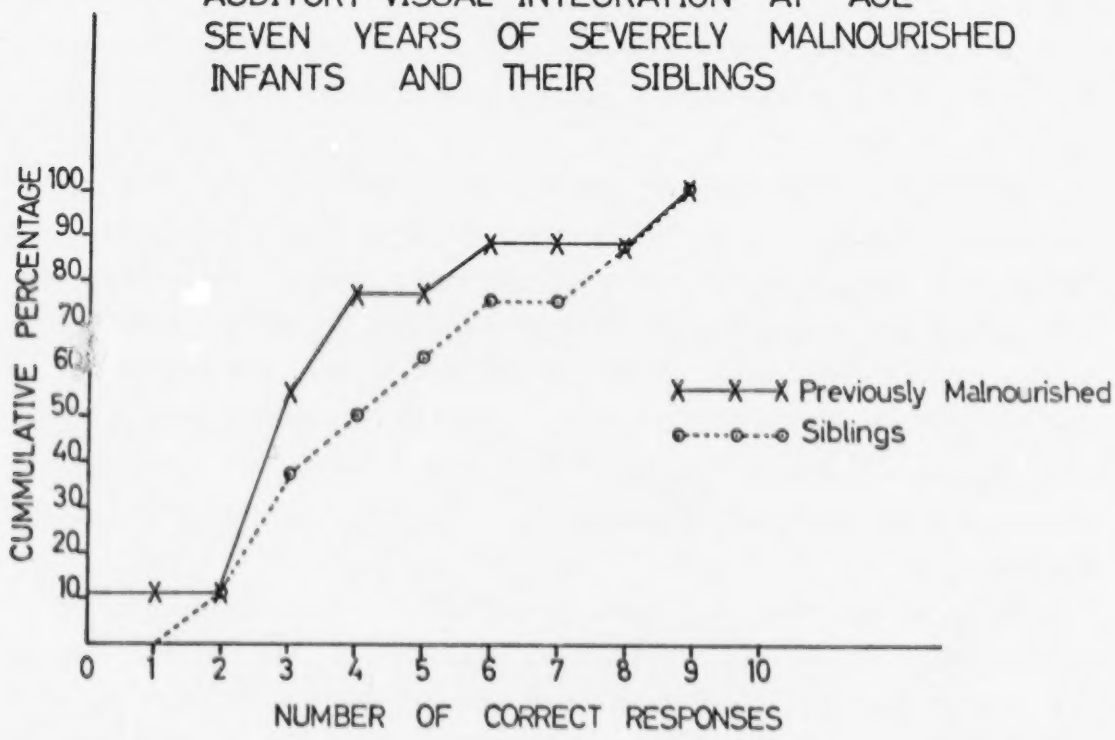


Figure 10

AUDITORY-VISUAL INTEGRATION AT AGE SEVEN YEARS OF SEVERELY MALNOURISHED INFANTS AND THEIR SIBLINGS



lature as its principle components. In the test situation, kinesthetic information was provided by placing the subject's preferred arm behind a screen, and with the arm out of sight, passively moving it through a path describing a geometric form.

Figures 11, 12 and 13 show the proportions of previously malnourished children and their siblings making errors in the identification of identical or non-identical forms at ages 5 to 7. It is evident that significant differences in accuracy of judgment exist always in favor of the siblings.

Research on experimental animals has clearly shown that malnutrition per se is capable of producing physical, biochemical and functional changes in the central nervous system. The effects are most marked and less transient when the episode of malnutrition occurs at the time of most rapid growth of the brain when the increment is due mainly to cellular hyperplasia. Changes in nucleic acid and protein content of human brains of marasmic infants, as reported by Winick, et al, also point toward malnutrition as the cause of the alteration.

The results that had been presented strongly suggest that an episode of chronic severe malnutrition in early life would increase the risk of scoring, both in intelligence tests and in the level of neurointegrative development, quite below the expected values of the specific socioeconomic class of the children under study.

It is important to consider that the findings are not conclusive proof of a causal relationship between deficient nutrient intake and mental retardation. It has been previously stated that malnutrition in humans may affect indirectly the function of the central nervous system through loss of learning time, interference during critical periods of learning, and changes in motivation and personality. The finding of better scores in siblings and matched controls speak against the social and familial environment as main causative factors, but do not exclude microenvironmental circumstances which may act early in the life of the child before the episode of chronic malnutrition, nor the possible effects of hospitalization which may constitute a period of restricted stimulation with its known adverse conse-

Figure 11

ERRORS IN JUDGMENT OF NON-IDENTICAL FORMS IN THE VISUAL-KINESTHETIC MODALITIES AT 5 YEARS OF AGE.

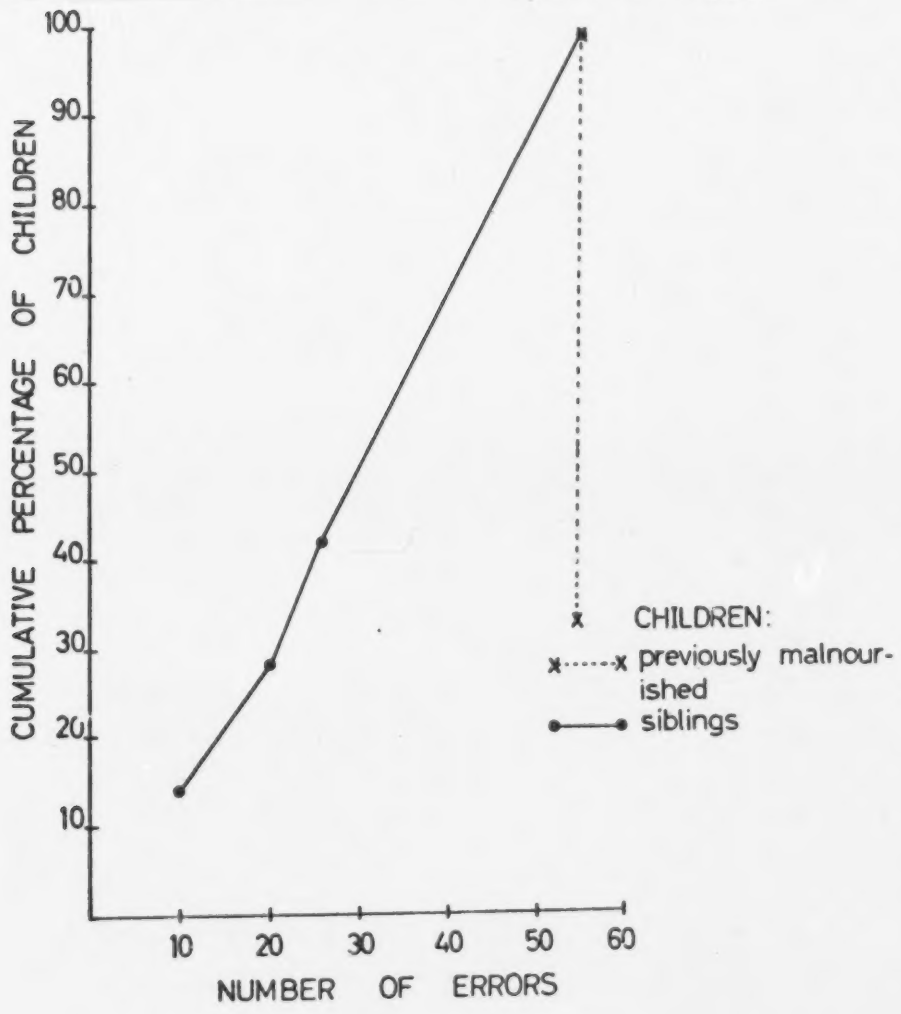


Figure 12

ERRORS OF JUDGMENT OF IDENTICAL FORMS IN THE VISUAL-KINESTHETIC MODALITIES AT 6 YEARS OF AGE.

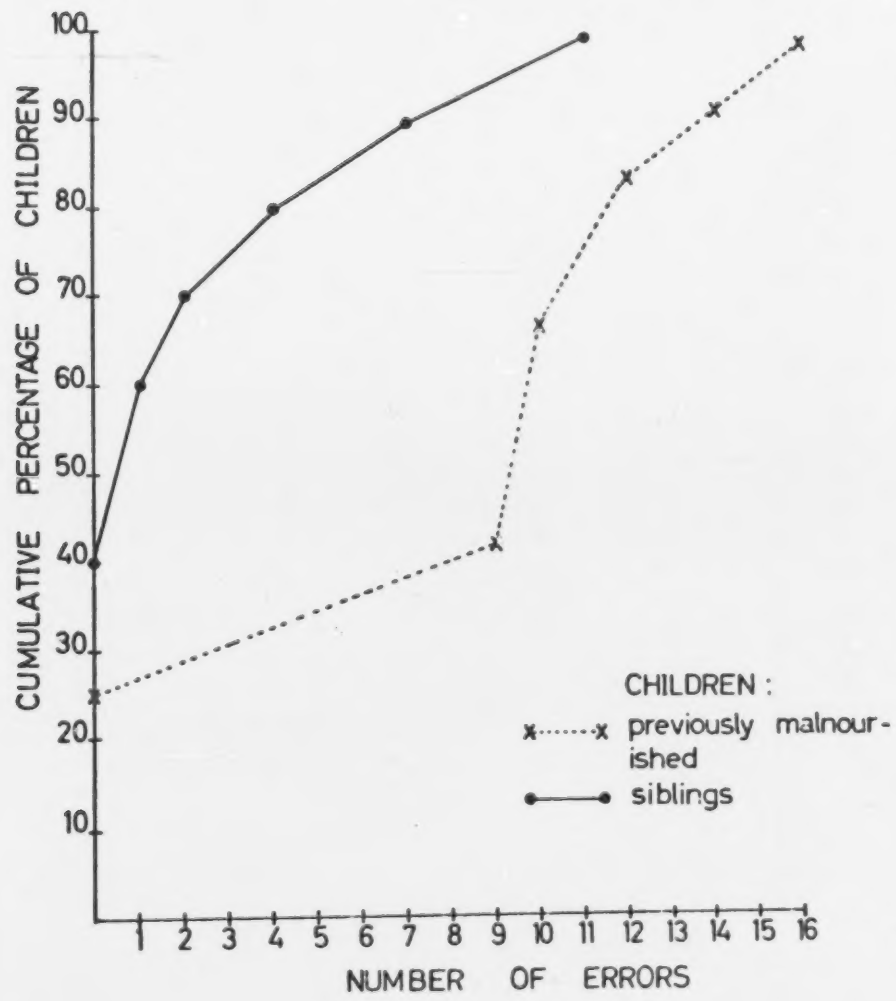
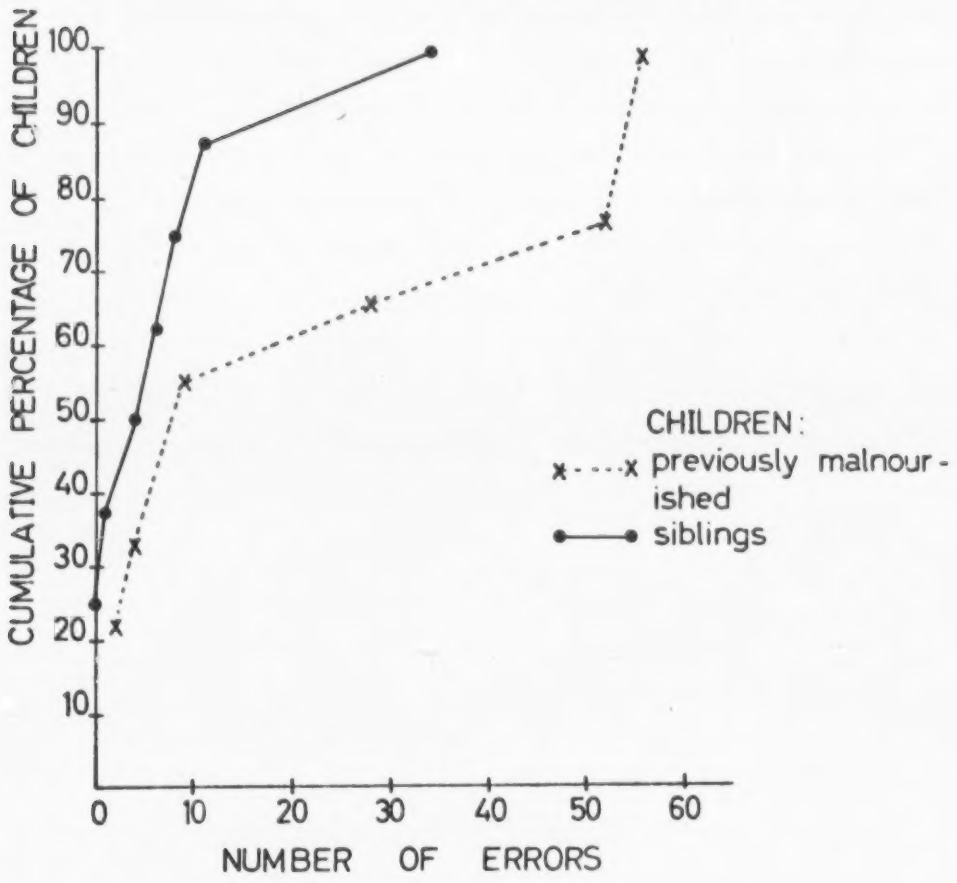


Figure 13

ERRORS IN JUDGMENT OF NON-IDENTICAL FORMS IN THE HAPTIC-KINESTHETIC MODALITIES AT 7 YEARS OF AGE.



quences for later development.

Aside from the pending decision as to whether or not malnutrition per se can cause central nervous system damage, it is evident that children who have survived the severe forms of this disease show alterations of brain function which clearly place them at a higher risk of failure to profit from school exposure.

One of the main differences between learning in humans and learning in other animal species is that only humans have demonstrated the capacity to receive and transmit knowledge to other members of the species, avoiding in this manner the need of experimenting with actual noxious agents and environments. Through the use of the oral and written language, knowledge acquires a hypothetical form saving time for the learner who is no longer required to engage himself in actual trial and error during the process of knowledge acquisition.

It becomes apparent that children who survived a severe episode of chronic malnutrition having interference with the adequate development of reading and writing are at a higher risk of failure to profit from the cumulative knowledge available to the human species in general, and to their socioeconomic group in particular.

DIETARY INTERVENTION IN MAPLE SYRUP URINE DISEASE AND PHENYLKETONURIA

Harry A. Waisman* and Eleanor S. Brown**

I am interested in malnutrition from both the patient's standpoint and from an experimental point of view because I think there is much involved in understanding malnutrition, mental retardation, and the influence of both in the world today. To those of us who have been working in nutrition for a long time, it is good to see a sudden, upsurging interest in malnutrition. We knew about this problem 25 to 30 years ago, and under-industrialized countries recognized it long before that. Although we knew that the problem existed in the United States, it took the country until just recently to recognize it. The familial nature of most mental retardation has also become clear. If you look back in most families with mental retardation there is a cousin, a niece, an aunt, or somebody else with mental retardation. We cannot run away from it.

It is very interesting that the development of organic chemistry, biochemistry, genetics and medicine all worked in different directions and then came together to form what we now call the study of inborn errors of metabolism. This field finally brings together various disciplines and has very practical usage because there are things that we can do about metabolic disorders. If you improve an individual's nutrition, without a doubt you can improve his mental ability. If an inborn error of metabolism which is a mistake made by the body, is recognized, then a great deal can often be done to alleviate that cir-

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**Dr. Harry A. Waisman died on March 19, 1971. This lecture was taped, and later edited by Dr. Eleanor S. Brown, Joseph P. Kennedy, Jr. Laboratories, University of Wisconsin Medical Center, Madison, Wisconsin 53706

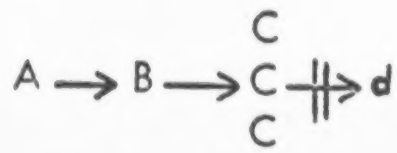
cumstance.

The first publication on inborn errors of metabolism was in 1909 and was written by a Dr. Garrod. Following his work he was knighted to Sir Archibald Garrod. He discovered the concept of this type of disease which he named inborn errors of metabolism. His Croonian lectures before the Royal College of Physicians were delivered in 1908. The most recent lecture of this Croonian series, which is an age-old series in England, was given by C.P. Snow.

An inborn error of metabolism is just what it says; the body makes a mistake in a metabolic process, and, instead of having an orderly progression from A to B to C to D, a block occurs:

Error of metabolism

or



Metabolic block

There is an enzymatic deficiency. There is some genetic difficulty in making a single protein which is an enzyme; regular metabolism stops, and everything piles up in front of that particular block which is shown by the "c's". Some of the inborn errors of metabolism can be successfully treated, such as PKU (phenylketonuria), Maple Syrup Urine Disease (branched chain ketoaciduria), Histidinemia, Wilson's Disease, and Homocystinuria. I want to talk about just two of these to illustrate what can be done if something is known about the child, about genetics, about pediatrics and about biochemistry. One can actually prevent the mental retardation which would otherwise occur in some of these conditions if the disorder went unrecognized and the child remained untreated early in life. Table I shows that in inborn errors of metabolism, an elevation of a substance usually occurs in the blood

TABLE I
PLASMA AND URINE AMINO ACIDS IN INBORN ERRORS OF METABOLISM

Amino Acid	Urine (mg./24 hr.)		Plasma (mg./100 ml.)	
	Patient	Control	Patient	Control
Homocystine	7.2-16	0	0	0
Agrininosuccinic Acid	1500-3000	0	4.4	0
Histidine	400-660	10-200	8.0-15	0.7-1.7
Phenylalanine	320-1000	1-18	5-100	1.0-1.7

or urine. For example, in inborn errors of phenylalanine metabolism, the concentration of phenylalanine rises in the blood so that the patient can have levels of 15, 20, 40 or 80 mg/100 ml. It must be higher than 20 to be considered classic PKU. We now feel that a patient who has a phenylalanine level of 20 or less, has something other than classic PKU. I will elaborate on this later. The same is true for histidinemia; the blood level is 8 to 15 times higher than normal. The curious thing is that in cases of homocystinuria the plasma level of homocystine may be normal, but urinary excretion may be high. We find many different types of inborn errors of metabolism.

We have been treating a little girl with Maple Syrup Urine Disease (a branched chain amino acid abnormality). She is now five years old and is thriving very well. Her family is of interest. Somewhere in her ancestry her paternal great grandmother and maternal great-great grandfather, were sister and brother. The important thing is the influence this possibly had on the little girl we are now discussing. Possibly both of these ancestors inherited the same recessive gene from one of their parents, and this little girl eventually inherited 2 recessive genes, and therefore had the disease. She has a normal brother and a normal sister, but she had a little brother who died because there was no recognition of his disease when he was born. The child lived about 30 days with all the symptoms one expects in Maple Syrup Urine Disease. He was an acidotic child and had a sweet-smelling urine. He just did not eat well and finally died with convulsions and severe acidosis simply because the disease was not recognized. His sister has exactly the same disease, but her diagnosis was made much more accurately and sooner by a bright resident who knew that there was something wrong with the child. We were able to confirm his diagnosis.

You will be interested in knowing how we treat such a child. Maple Syrup Urine Disease is a rare inborn error of metabolism, probably much more rare than PKU. It is theoretically rather easy to treat if one simply eliminates most of the leucine, isoleucine, and valine from the diet. We give an adequate amount of calories in the diet (Table II)[1], and this is provided partly by fats and carbohydrates. We always give some milk to provide some natural protein. The natural

TABLE 11

DIET LOW IN BRANCHED-CHAIN AMINO ACIDS

Patient S.F. Age 15 months

CALORIES	110 cal. /kg.
NATURAL PROTEIN (MILK, ETC.)	1.3 gm. /kg.
LEUCINE, OPTIMUM (IN NATURAL PROTEIN)	120 mg. /kg.
AMINO ACID MIX	1.8 gm. /kg.

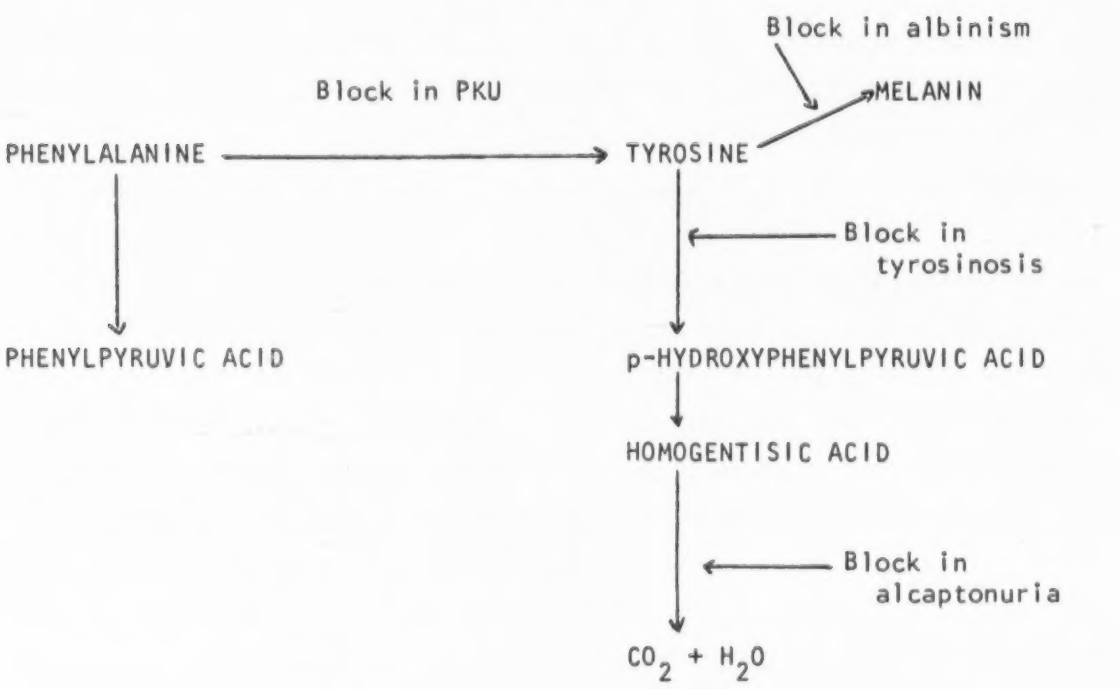
protein provides the necessary leucine, isoleucine, and valine (branched chain amino acids) so we leave these out of the mix of amino acids, vitamins and minerals. We give this mix in an adequate amount so she gets the normal amount of all the amino acids with the exception of the branched chain amino acids.[2] The amino acids, vitamin, and mineral mix is made up by one of our dietitians and given to the mother. The mixture is fairly easy to make.

Returning to the little girl, we see that her growth is really within two standard deviations of the mean, but it tends to follow the 10th percentile, and is similar to that of her sister's. The metabolically disordered child's performance jogs a bit, and several times her weight has dropped rapidly to the 3rd percentile. She has a drop, comes back, then she drops again. All this is due to the fact that whenever she has an acute upper-respiratory infection, such as a virus brought home from school by her older brother, she is thrown out of kilter. The upper-respiratory infection causes her to become acidotic and she refuses to eat. Once she refuses to eat or vomits her food, it is as though she were never diagnosed; she gets into severe difficulty and we have to save her by a variety of heroic pediatric means that we think we know something about. Fortunately her head circumference has continued to grow normally, and, even though height in her family is on the small side, she is thriving within the normal percentiles. Of course she is able to talk and go to school. She is in kindergarten and is now even willing to talk to me. I am the one who always drew blood from her before, and we do not win friends by drawing blood on preschool children. Now we are friends, though, and she talks to me and is pleasant.

This is one disease which can be dealt with fairly adequately only if it is diagnosed and treated early. I admit there are not too many such cases, living, perhaps less than 50 to 100 in the world, but there are two of them in Wisconsin. This girl is one of the few who has remained alive and mentally normal because she was diagnosed early and we were right on top of the problem nutritionally most of the time.

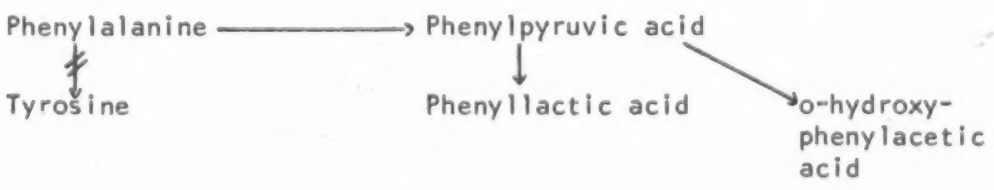
A chemical illustration of the inborn errors of metabolism occur-

ring with phenylalanine abnormalities is as follows:



Phenylalanine is metabolized to tyrosine when it is not blocked. If that reaction does not occur, it means the phenylalanine hydroxylase enzyme is missing. Phenylalanine, then, has to go in another direction; it forms phenylpyruvic acid (a phenylketone) which accumulates in the urine and gives phenylketonuria its name. There are other diseases resulting in inborn errors of metabolism due to errors in the pathway of phenylalanine metabolism: alcaptonuria, albinism, and tyrosinosis. Thus we find four inborn errors of amino acid metabolism which are related to phenylalanine and its metabolites.

I am only going to talk about PKU as an illustration of the absence of an enzyme. The formation of tyrosine is blocked due to the absence of the enzyme, and phenylalanine must be metabolized in another direction:



We can diagnose this easily by analyzing urine for these other compounds. Of the 50 states there are 40 that have mandatory laws for testing for PKU. Doctors do not like to be forced to test for anything, and, therefore, the laws are not well written nor are they well pursued. Since they are not followed very well, the diagnosis is often not pursued properly even though testing is routinized. You get too many false positives and too many false negatives, but in most states, at least, a test is being done. The incidence of PKU is about one in 13,000 live births, so it is a meaningful number. We have in this country 18 centers gathered together in a Collaborative Study of PKU, and you will be interested to know that Michigan is not in the study by their own choosing. Other important places like New York City have no one representing them in the study, but that is their problem. We are attempting to find the best dietary treatment for these children. Those of us in the Collaborative Study are convinced that dietary treatment does, in fact, prevent severe retardation. Let me say here and now that I have no doubts that the treatment is of value despite what you have read in the literature; despite the meetings you have gone to; and despite all of the more bombastic speakers than I who deride the treatment.

The way we now make a diagnosis for PKU is that the blood level of phenylalanine has to be above 20 mg/100 ml:

CHEMICAL DIAGNOSIS OF PKU

1. PLASMA PHENYLALANINE > 20 mg/100 ml. AFTER SEVERAL DAYS ON NORMAL DIET.
2. PLASMA TYROSINE LEVELS NORMAL.
3. USUALLY POSITIVE URINE TESTS FOR PHENYLKETONES.

You must have a normal tyrosine level, and there is usually a positive test for ketones in the urine. Many of you were born in hospitals, and I will wager that when you were born your mother stayed in the hospital

for 10 days. But now all of you younger girls who are still going to have children probably will not stay in the hospital for more than 2 or 3 days. The girls must be getting stronger, or the hospitals are short of beds, or something is going on. So some infants go home before there has been adequate milk intake to test for PKU. There is not enough phenylalanine in breast milk to raise the blood phenylalanine level rapidly and often there is not enough intake of formula to cause the phenylalanine level to rise much above normal. So if the test is done, according to the laws, before the baby goes home, it may be a useless test in some cases. For that reason, we miss some cases of PKU in this country unless the doctor who sees the baby at four weeks of age and at six weeks of age does another Guthrie test on the blood. By that time it cannot really be negative any more if the child has PKU. As we learn more about this disease, we find that PKU is not a simple disease. The hyperphenylalaninemia or high blood level which exists, can also exist without ketones. We can call the whole spectrum of the disease hyperphenylalaninemia (which means high phenylalanine levels in the blood). On one end we have classic PKU and on the other transient hyperphenylalaninemia which disappears as the child matures. There are also many cases of persistent hyperphenylalaninemia in which the blood level remains below 20 mg/100 ml.

If you compare classic PKU and the milder hyperphenylalaninemia, you can certainly tell the difference because the blood level seldom goes as high as 20 in the second case. Patients with mild hyperphenylalaninemia often do not have phenylketones in the urine; they usually do not have the typical rash, convulsions, or history of retardation in the family, and, therefore, it is theoretically not hard for somebody who knows something about it to differentiate the two types of diseases. However many patients have an intermediate type of disease and the diagnosis is not clear (Table III). If you look at the different types of hyperphenylalaninemia, there are: transient hyperphenylalaninemia (which can only be identified after the phenylalanine level has returned to normal), persistent hyperphenylalaninemias (PKU and mild hyperphenylalaninemia), transient tyrosinemia, and tyrosinosis. (Children with histidinemia may have a

TABLE III

DIFFERENTIAL DIAGNOSIS
OF HYPERPHENYLALANINEMIA

	HYPERPHENYLALANINEMIA	
	CLASSICAL PKU	WITHOUT PKU
AGE AT ONSET	FEW DAYS AFTER BIRTH	FEW DAYS AFTER BIRTH
INITIAL PLASMA PHENYLALANINE	20-60 mgm%	12-20 mgm%
PHENYLPYRUVIC ACID	+	-to+
o-(OH) PHENYLACETIC ACID	+	-to+
RASH	-or+	-to+
CONVULSIONS	-or+	-to+
FAMILY HISTORY OF TYPICAL PKU	-or+	-to+

positive urine test for PKU, but this is due to histidine metabolites, and the blood tests for phenylalanine are normal.) Every one of these can now be clearly differentiated so that you do not make a mistake and treat a patient who does not have PKU. If you have a patient with a higher than normal blood level of phenylalanine, you have to do more tests or follow the baby. Just the other day a patient was sent in with a blood level of 6. The mandatory tests came back positive because anything over 4 is positive. We watched this baby and her level is still 6, two months later. It may be three months before it goes down or else the child may always have 6 mg which is 6 times above normal. At that level, though, it is not harmful and it is never going to damage that baby's brain. That I can be sure of on the basis of our experience. You just have to understand that there are variations. Nothing is all or none as we learn in physiology. That something either happens in a typical way or does not happen at all is not true in biology. In Table IV the plasma phenylalanine level in PKU is described as over 30, while in hyperphenylalaninemia it is less than 23 mg/100 ml. Some children have levels between 20 and 30 during the first few months and these gradually decrease so that they remain below 20. We do not like to make a diagnosis of typical PKU until we have watched and treated the child for 6 months or a year.

Mead-Johnson, to put in a commercial plug, makes a special milk low in phenylalanine, called Lofenalac. It has all the vitamins, minerals, and other amino acids, but only a minimum amount of phenylalanine. This is a great milk to provide almost everything that the growing PKU infant needs. But we <u>have</u> to add foods containing <u>phenylalanine</u>, and to make sure we give the right amount we have to measure the levels of phenylalanine in the blood. We have phenylalanine equivalent systems (exchange systems) which have been described by a variety of dietitians. Different fruits, vegetables, and cereal products contain certain amounts of phenylalanine and protein, and when you know how much phenylalanine a particular child needs you can substitute one food for another, such as so much squash instead of so many green beans. You also supplement the diet with carbohydrates and

TABLE IV

PKU
DIFFERENTIAL DIAGNOSIS

	Guthrie	plasma Øal mg/100ml	plasma Tyr. mg/100ml
Normal	-	< 3	< 2
PKU	+to+++	30 to 70	< 2
Hyper Øal	+	6 to 23	< 2
Transient Tyrosinemia	+	5 to 15	30 to 50
Tyrosinosis	-	< 3	3 to 12
Histidinemia	-	< 3	< 2

fats while maintaining a low protein diet, and the baby grows very well w th only the required amount of phenylalanine. As an infant grows, of course, he will require fewer amino acids/kg body weight, as Selma Snyderman showed years ago. There is a great deal of individual variation (Fig. 1).[3] We have one little boy who can take lots of phenylalanine and it will not raise his blood level very much. On the other hand there is another little boy who, if given just a little bit too much, will have blood levels well above 10 mg/100 ml which is higher than we want it.

We like to keep blood levels between 1 and 5 mg percent or between 5 and 10 mg percent. In the Collaborative Study we have these two ranges, and we attempt to keep patients within one of them. Dietary control, especially early in life when the brain is growing rapidly, is very important. There is no problem in giving recommended daily calorie allowances because you can always add fats or carbohydrates. However we have usually given somewhat less than the recommended daily allowance of calories (Fig. 2)[4] and the children grow well on this diet. An adequate "protein" intake is also no problem. The child gets this mainly from the Lofenalac. Our patients generally get 2 times the Recommended Daily Allowances of "protein" during the first 3 months (Fig. 3)[5], but the intake/kg body weight gradually decreases. It is important that the child gets enough food for good growth. This is just what Dr. Cravioto spoke about. You should attempt to attain normal growth for optimum intellectual development. If you overtreat a baby and give him too little phenylalanine he will be deficient in phenylalanine and malnourished. The criticism raised in the literature that treatment is no good is based on the fact that earlier workers overtreated their patients. They made them phenylalanine-deficient in their zeal to keep the plasma phenylalanine level low, and they kept it so low that the child did not grow. We did the same thing until we got smarter. We now know that patients with low phenylalanine levels did not maintain their growth curves, while those with slightly elevated phenylalanine levels grew better and had better IQ's or DQ's (Table V).[6] Those with good general growth also had normal head circumferences, while those with poor growth had small head circum-

Figure 1

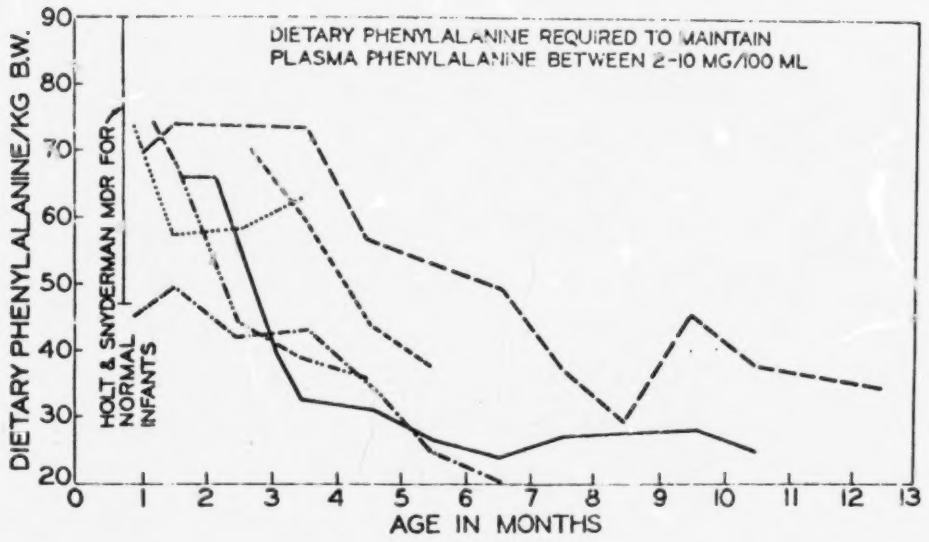

DIETARY PHENYLALANINE REQUIRED TO MAINTAIN
PLASMA PHENYLALANINE BETWEEN 2-10 MG/100 ML
DIETARY PHENYLALANINE/KG B.W.
HOLT & SNYDERMAN MDR FOR NORMAL INFANTS
AGE IN MONTHS

Figure 2

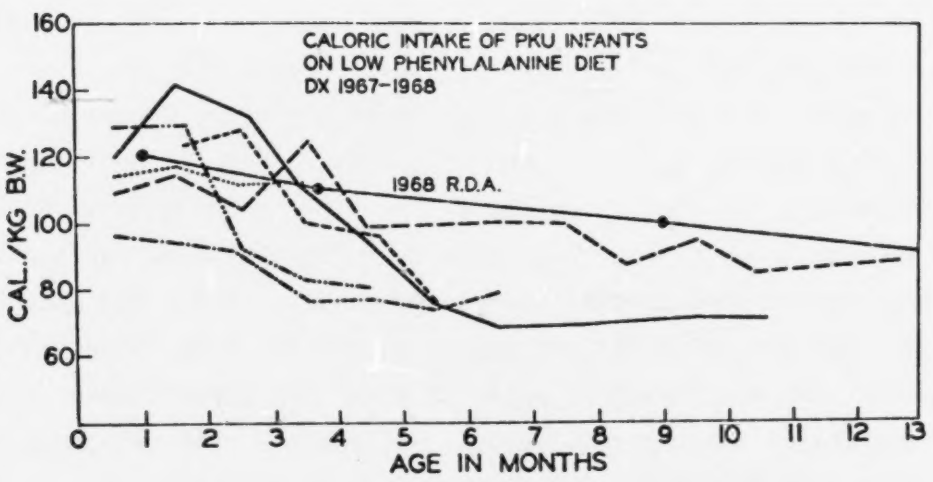


Figure 3

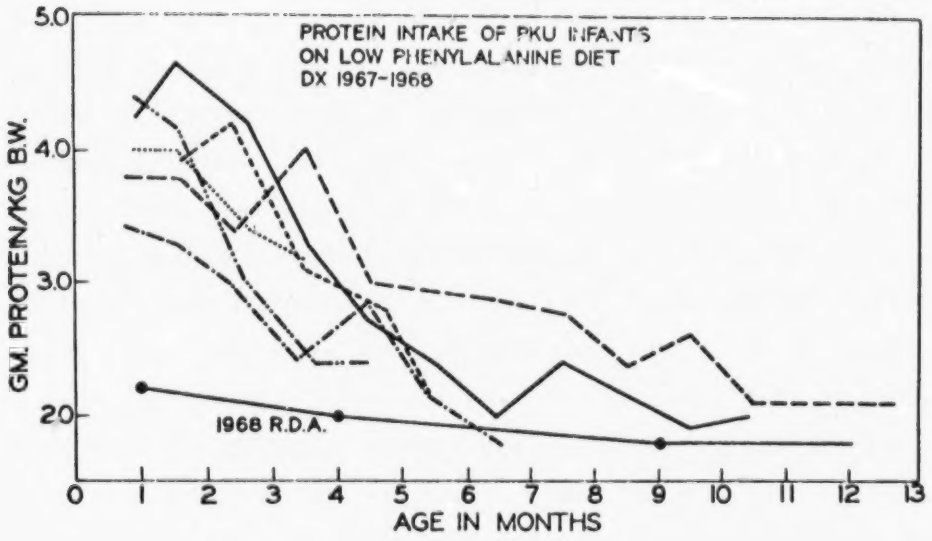


Table V

PKU PATIENTS

NUMBER OF PATIENTS	PHENYLALANINE INTAKE (mg/kg Body wt.)		AVERAGE PLASMA LEVEL mg%	GROWTH	AVERAGE DQ (1 yr.)	DQ (%sib IQ)
	3 mo.	4-6 mo.	0-6 mo.			
5 - 8	25	30	0.9	POOR	88	79
11	55	36	7.1	GOOD	105	102

ferences and low IQ's or DQ's (Table VI).[7] This is just what is expected since one cannot over-restrict a diet and expect good responses.

The later you start treatment the lower will be the IQ. In other words, the first few months of diagnosis and treatment are very important. If you diagnose a child at 18 or 24 months of age he has already incurred so much brain damage that you usually cannot expect his IQ to reach much more than 50. On the other hand, if a diagnosis is made early and the child is treated early there is no doubt that you can maintain a mental level very close to that of his non-PKU siblings. On the left side of Figure 4 we show a little girl who was diagnosed at 10 weeks of age. She is fourteen years old now, and her blood levels were kept below 8 most of the time. Sometimes it went higher than 8, but her IQ was about 110. She has a retarded brother with untreated PKU who is in one of our state institutions. She also has one normal brother. We have, within the same family, the advantage of comparing both treated and untreated siblings. We have another little girl who was diagnosed at one month of age (Fig. 4, center). She came into our hospital because of failure to thrive, and everybody examined her, including myself, without realizing she had a metabolic problem. She was vomiting and having problems feeding, so we x-rayed her esophagus to see if there was any obstruction. Finally we did a test for PKU and it was terribly positive. Her diet was reasonably well controlled but I feel maybe too well controlled. She was one of our first patients who I think was overtreated, and her IQ is now only about 60. We are not terribly proud of her. She demonstrates that we have learned something that we hope never happens again.

We also saw a cousin of the first little girl (Fig. 4, right). The mother and father in the two families are brother and sister, but the second set of parents did not bring their daughter in to be checked until she was one year old. We never had a chance to treat her early, so, of course, her IQ is only 80ish. Early treatment is important.

Here is another interesting case (Fig. 5). In a survey I made in our colonies for the retarded we found two siblings (C1 and C3) who were terribly retarded. We then wrote the parents telling them

Table VI

GROWTH OF PKU PATIENTS TREATED BEFORE 4 MONTHS OF AGE

	NAME	IQ	PRESENT AGE (YRS.)	HEAD GROWTH PERCENTILE AT AGE ≤ 3 YRS.
(GOOD) 50-90%-ile	K.K.	104	1/3	[illegible]5
	A6	93	6 1/2	25
	C1	91	3 1/2	90
GROWTH 25-50%-ile	C5	92	7 1/2	10
	S.C.	108	3/4	25
	R.R.	85	1/2	25
	D.B.	112	1 1/3	10-25
	E3	110	9	3-10
(POOR) <25%-ile	B3	45	6 1/2	<3
	I1	32	3	<3
	D4	70	9	3
	M.G.	36	1/2	10

Figure 4

COMPARISON OF 3 TREATED PHENYLKETONURIC CHILDREN

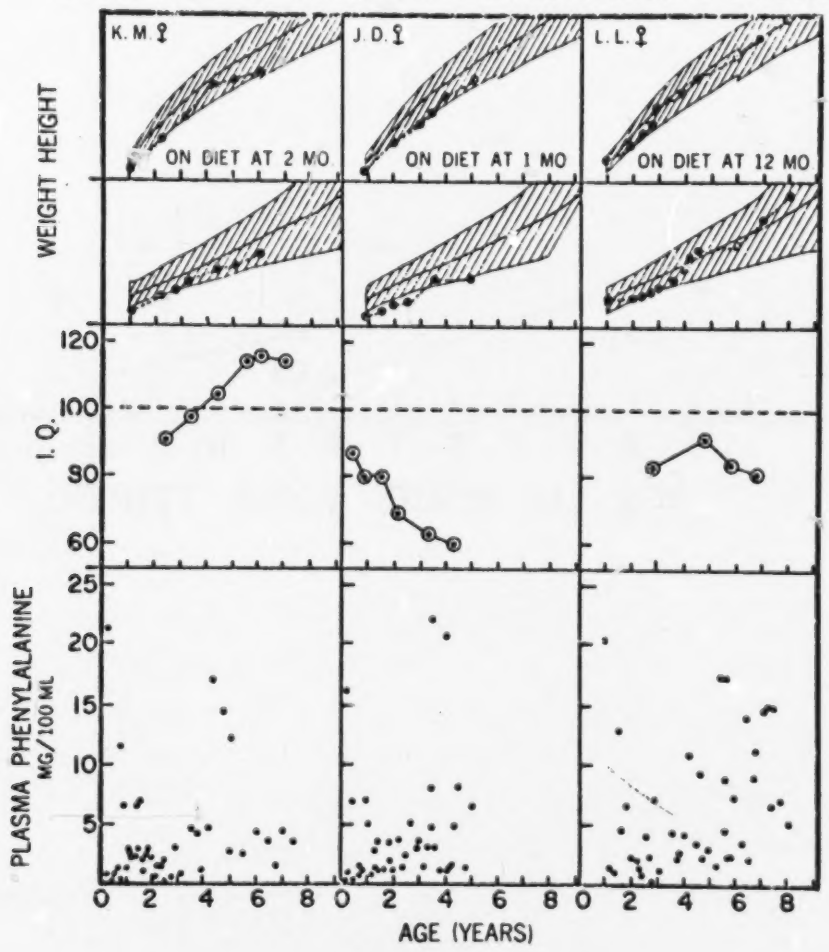
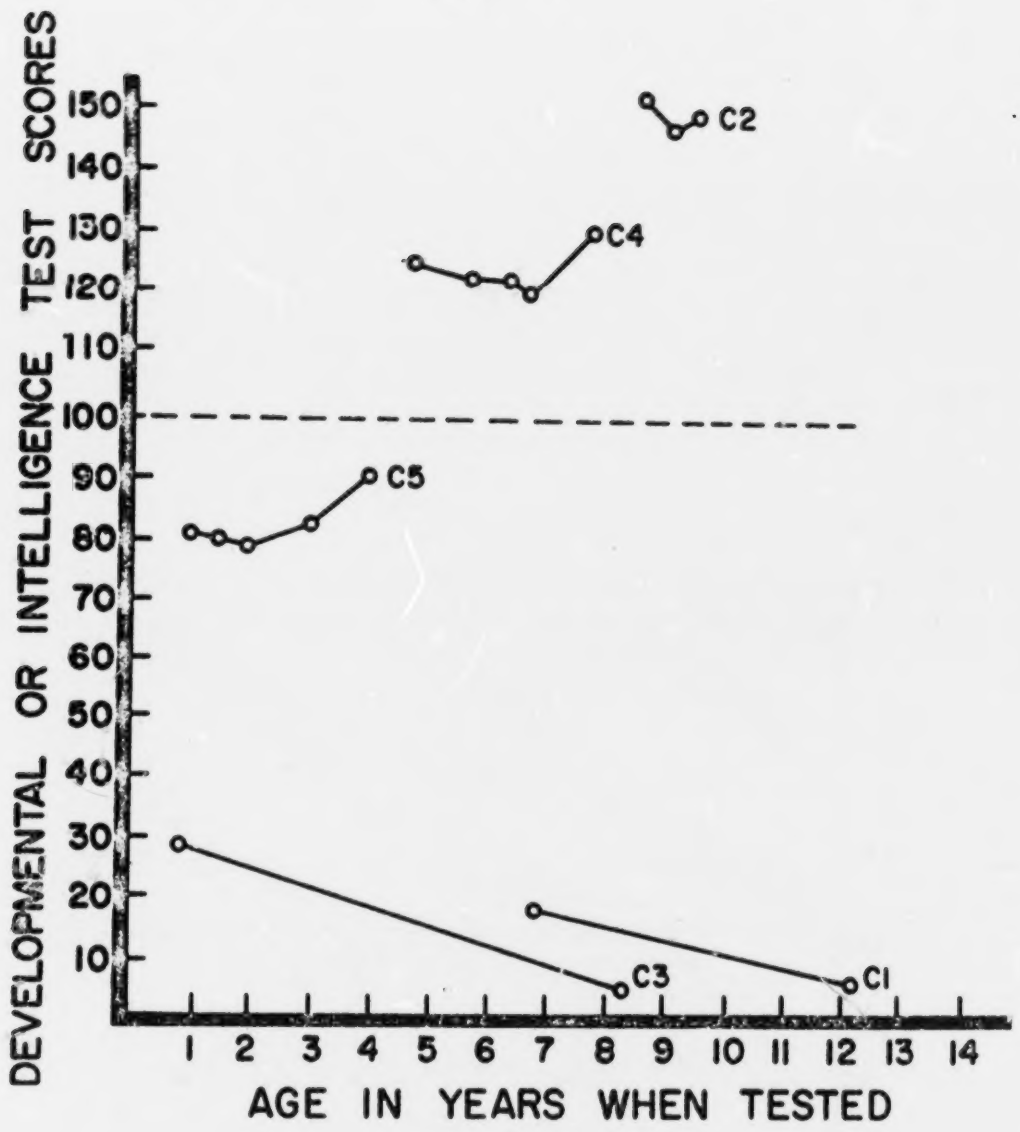


Figure 5

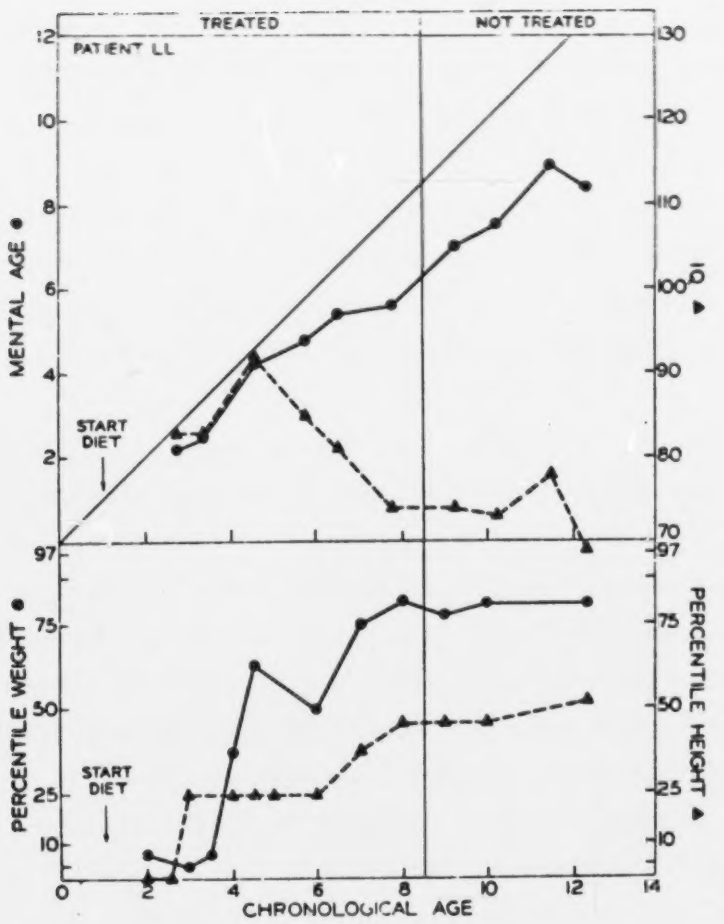

TEST SCORES
DEVELOPMENTAL OR INTELLIGENCE
150
140
130
120
110
100
90
80
70
60
50
40
30
20
10
C2
C4
C5
C3
C1
1 2 3 4 5 6 7 8 9 10 11 12 13 14
AGE IN YEARS WHEN TESTED

we knew the cause of the retardation and asked them to come in and talk to us. We explained metabolic disorders to the parents, and I found out the mother was pregnant again. A boy was born with PKU, and we put him on a diet right away. He is infinitely better than his two sisters who are in the institution, but he did not progress as well as possible because he was overtreated, and he now has an IQ of 92 (C5).

He also has two other sisters (C2 and C4) with IQ's of 130 and 150. Now is it best to compare him with his superior siblings or with his retarded siblings? I would like to compare him with the retarded ones because I think we have done much to keep him from a similar condition.

A good question is: How long should these kids be kept on the diet? We really do not know for sure. We take some of them off at six years of age for a lot of reasons. They begin school and have difficulty maintaining their diets during snack and lunch periods. It is socially and emotionally difficult to maintain a low phenylalanine diet once kids start going to school. We begin to liberalize their diets, and by 6 or 8 years of age allow them to eat anything they desire. We do not worry too much because we know that by 6 years of age the brain growth is nearly complete in size. Certainly 90 percent of the brain growth has occurred by this time. Several kids stopped their diets at 6, 7 and 8 years of age and their IQ's did not regress. The little girl we saw before who was diagnosed at one year of age stopped her diet at 8 years of age. She has been off the diet 5 years and her IQ has not changed significantly (Fig. 6). We have considerable data showing that children do not really regress during the first year off the diet. Neither do they have a rash or convulsions. They have an odor and they excrete phenylketones. Their blood phenylalanine is still high, but they are not in any way as retarded as they would have been if untreated. Stopping the diet is a question subject to much debate. Some people feel we ought to maintain the diet until children are 15 years old and the myelinization of all their nerves is nearly complete. I think that is unrealistic. I do not think you can do that. Stopping the diet really does not do any great harm immedi-

Figure 6

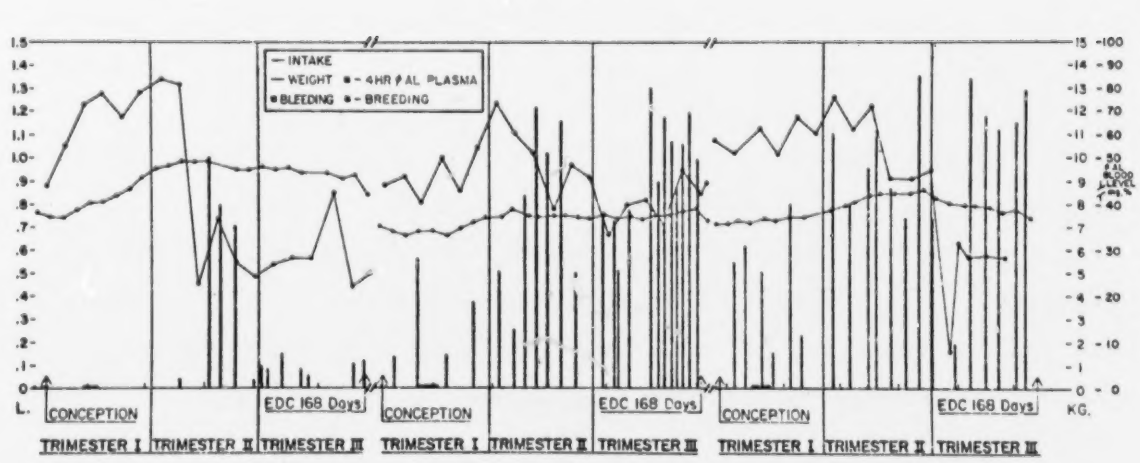

TREATED
NOT TREATED
PATIENT LL
MENTAL AGE ●
IQ ▲
START DIET
PERCENTILE WEIGHT ●
PERCENTILE HEIGHT ▲
START DIET
CHRONOLOGICAL AGE

ately, but we do need to see what happens over a longer period of time and no one has much data on this as yet.

There is an important problem here that deserves stress. What happens when these girls grow up, become normal or near-normal girls, and they get married and want children? This has always been a real problem for us. I know their biochemistry will not change; the genetics will not change. We know that there is going to be difficulty because children have already been born to mothers with PKU. There is an institution in Tennessee with the interesting name of Clover Bottom, and a doctor there surveyed his patients and found a mother and five children, all of whom were retarded[8]. The mother's retardation stemmed from PKU, and all her children were retarded <u>not</u> because they had PKU, but because of the maternal biochemistry which damaged the fetus. We also found this to be true in studies we did on monkeys. We fed monkeys high amounts of phenylalanine and produced a biochemical condition of hyperphenylalaninemia in the mother monkey. This mother monkey had three pregnancies (Fig. 7), and her blood levels of phenylalanine were sometimes as high as 60-70 mg/100 ml (shown as bars in the figure). When the infants from several mother monkeys were born we found that birth weights of the infants were lower when the mother's plasma phenylalanine levels had been higher. For example, when the mother's blood level was 40-60 mg, the baby had a birth weight of about 350 g. When the mother had a blood level of 20, the baby had a birth weight of about 475 g. The normal birth weight of monkeys is between 450 and 550 g.[9] It seems as though high levels of phenylalanine do affect the size of the baby.

What is even more interesting is how much of the phenylalanine goes across the placenta to the developing fetus. The placenta acts like a pump for the benefit of the growing baby.[10] If there is a normal amount of phenylalanine in the mother, twice as much goes across to the baby. The amount in the baby's blood is about 1 1/2 to 2 times the level in the mother's blood and when the mother's level is too high, the baby's level will be even higher. Throughout gestation the brains of our infant monkeys were bathed in phenylalanine. To give more examples of this we had a mother monkey with a phenylalanine

Figure 7


INTAKE
WEIGHT ● - 4HR ℘AL PLASMA
BLEEDING ● - BREEDING
L.
KG.
CONCEPTION
EDC 168 Days
TRIMESTER I
TRIMESTER II
TRIMESTER III

level of 22 and her baby had one of 45 (Table VII).[11] Two other mothers had levels of 27 and 11 respectively; their babies each had a level of 43. High levels such as this apparently damage the brain. After birth these infant monkeys grew normally because they received no additional phenylalanine (Fig. 8). These monkeys were tested by Dr. Harlow[12] and his psychology students. He demonstrated that errors made by these infants, even though they are on a normal diet after birth, reflected in-utero damage (Fig. 9). They do not perform learning tests as well as control animals. Thus, there is no doubt that these babies were affected in-utero.

There is a lady who is not typical PKU; she just has a high blood level of phenylalanine. She acts as a crossing guard; she cooks for her family; and she is a great mother, though a little on the slow side in arithmetic. She has 17 mg of phenylalanine in her blood. She was pregnant four times, and every one of her children is retarded.[13] This happened for the same reason that the infant monkeys were retarded. Every time this woman was pregnant, she pumped twice as much phenylalanine into her developing babies as she had. The data (Table VIII)[14] show that the mother has an IQ of 94, and her kids seemed to grow normally physically, although their head circumferences were small at birth. Their blood levels are normal, (intermediate between the normal and carrier range) and there seems to be nothing physiologically wrong with them, although their IQ's are cartainly not optimal. The father has a superior IQ which is of interest. Some men like to marry women who are a little slower than they are. It is easier for them. The mother's phenylalanine level is, of course, way up and the father's is completely normal. These kids should be carriers of PKU or hyperphenylalaninemia, if our understanding of the genetics is correct. We tested the father and all the kids by several carrier tests (Brown, E.S. and Waisman, H.A. unpublished). We are fairly certain that the father is not a carrier at all. Some of these kids are carriers by one test and not by another. If these retarded kids should ever reproduce, they have a very good chance of having normal children.

Going back in the literature you will find about 60 offspring of

TABLE VII
CONCENTRATION OF PHENYLALANINE IN MATERNAL MONKEY SERUM AND IN FETAL CORD

MATERNAL DIET	NO. OF ANIMALS	PHENYLALANINE (mg/100 ml)	
		MOTHER	CORD
CONTROL	(8)	1.26±.49	1.68±.28
L-PHENYLALANINE (0.2-1.4 g/kg/day)	(1)	22.0	45.3
	(1)	11.8	43.1
	(1)	27.2	43.7

Figure 8

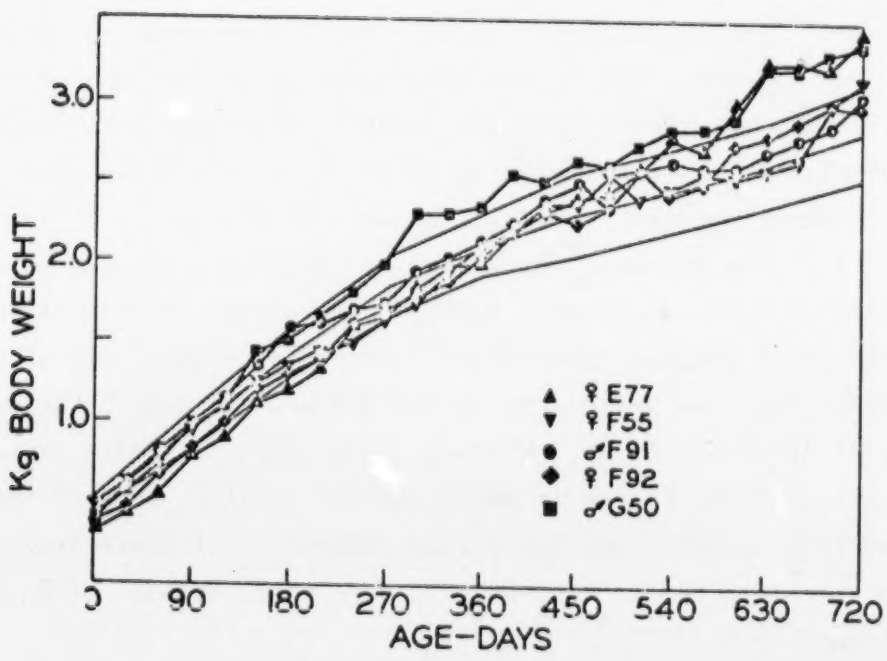


Figure 9

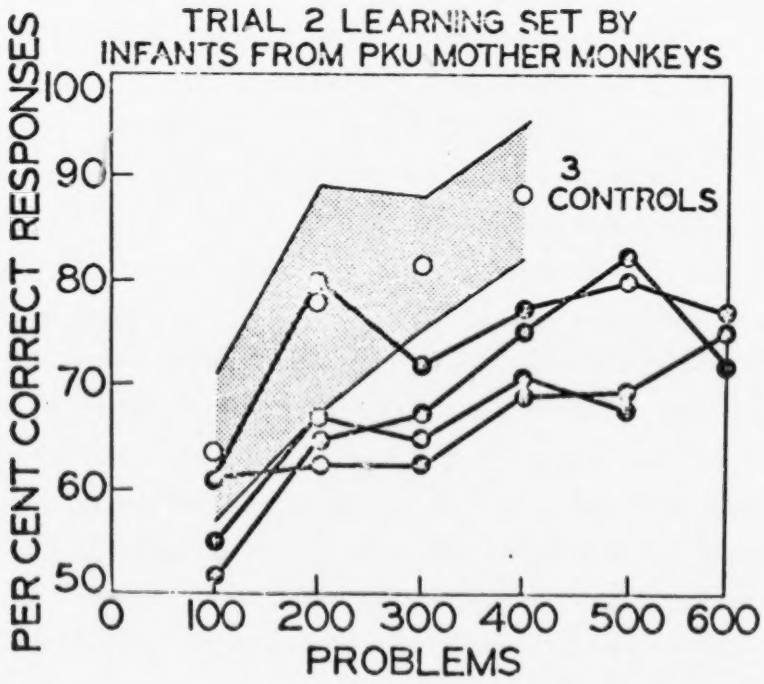


Table VIII

MATERNAL PKU

	DOB	PLASMA ϕAL	IQ
MOTHER-MRS. M		15-17	94
A ♂	FEB 55	1.2	75
B ♀	MAR 56	1.2	85
C ♀	JULY 57	1.3	64
D ♀	JAN 59	1.3	71
FATHER-MR. M		1.0	130+

mothers with PKU, and it is interesting that most of these children have low IQ's (Fig. 10)[15]. Dr. Hansen[16] at Columbia found the same thing; children born to 26 mothers with high blood phenylalanine levels had IQ's below what we consider normal (Table IX). There is a definite effect of this particular in-utero situation.

I have tried to demonstrate only two diseases. There are newer biochemical situations which take place and which make early diagnosis important. If you are going to help children with inborn errors of metabolism, and there are hundreds of them, diagnosis must be early. Some of you have heard of Tay Sachs Disease, and some of you may have heard of Krabbe's Disease. These too, are inborn errors of metabolism. We only know some of the enzyme deficiencies. We know that some of these diseases are helped by dietary treatment. For some, no dietary treatment is available and it is not yet possible to replace the missing enzyme. There are many unanswered questions, but many of the problems we have considered in the past to be insoluble may have a solution. For example, many of you who work in institutions know that whole families have retardation. It is not always because they are socially, culturally, or nutritionally deprived. There are some good families in which every child is retarded to some degree. Maybe once we know what to look for we can correct other forms of retardation. Our studies and successes with PKU, hyperphenylalaninemia, and maple syrup urine disease show that, at least in the area of inborn errors of metabolism, something can be done.

Figure 10

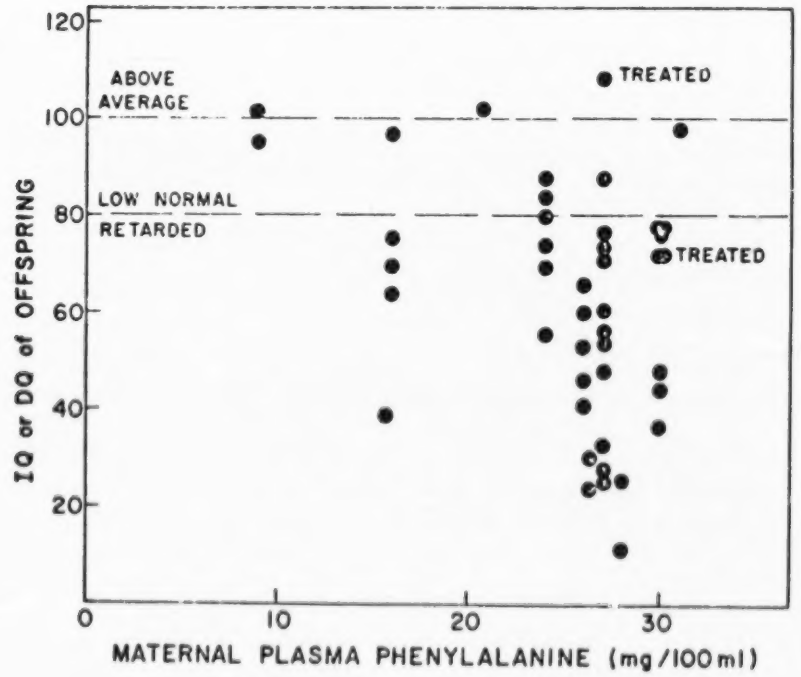


Table IX

DISTRIBUTION OF MENTAL LEVEL (AAMD CLASSIFICATION) AMONG THE BIOCHEMICALLY NORMAL PROGENY OF 26 HYPERPHENYLALANINEMIC MOTHERS

MENTAL LEVEL	NUMBER	RANGE OF TEST SCORES
NORMAL INTELLIGENCE	7	97-103
BODERLINE INTELLIGENCE	2	76-82
MILD RETARDATION	9	51-71
MODERATE RETARDATION	5	32-42
SEVERE RETARDATION	3	18-30

Holger Hansen - Epidemiological Considerations on Maternal Hyperphenylalaninemia.

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QUESTIONS AND ANSWERS

1. Q: Can a girl with a high phenylalanine level be put on a low phenylalanine diet during pregnancy to avoid damage to the fetus?

   A: Unfortunately, this is not easy to do because the taste of low phenylalanine diets makes them almost impossible to eat after one is used to a normal diet. This was tried in several cases. It may have helped the infants in several cases, but in others the diet may have caused malnutrition in the mother, and may have caused the poor growth and small head circumference observed in the infant.

2. Q: Is an infant born with a blood level of phenylalanine at 5 mg/100 ml put on a low phenylalanine diet?

   A: Absolutely not. Although a blood level of 4 mg is considered normal, variations from 5-10 mg will not cause brain damage. Only in cases where the level reaches 20 mg are infants put on restricted phenylalanine diets.

3. Q: How accurate are the PKU urine tests given in pediatric clinics?

   A: Several kinds of urine tests are given. They range from a chemical substance put on diapers to tests on urine specimens. Urine is never used as a conclusive test for PKU, however. If urine tests indicate the possibility of PKU, then a blood test must be given for a final diagnosis. Many cases of PKU are missed by urine tests especially during the first months of life when treatment is probably most important.

4. Q: What is the relative incidence of PKU among black and white children?

   A: While PKU is found in both black and white children, the incidence is lower in black children.

5. Q: What is excess phenylalanine due to?

   A: This is due to a deficiency of the enzyme phenylalanine hy-

droxylase. It is not known how the excess phenylalanine causes mental retardation, but one new theory suggests that it causes a tryptophan deficiency which affects brain-protein synthesis.

6. Q: How are high phenylalanine women encouraged not to reproduce?

   A: This varies individually, however, I feel such women should undergo tubal ligation and definitely not be allowed to reproduce. This applies especially to women who were once diagnosed as phenylketonuric but have since then been successfully treated.

7. Q: If the disease is caught early and a long enough time elapses, can a PKU woman reproduce normally?

   A: No, because the disorder is chemical, and while it may be controlled it will never change during the patient's life.

8. Q: Should PKU tests be repeated on infants at one month of age?

   A: Yes, 100%. PKU does not always show up during the first days of life and may go unnoticed until excessive brain damage has occurred.

INTERDISCIPLINARY PANEL PRESENTATION: SOLVING FEEDING PROBLEMS OF MENTALLY RETARDED CHILDREN

DENTIST-MODERATOR

Henry Kanar*

The topic this morning is an interdisciplinary panel presentation concerned with the feeding problems of mentally retarded children. We will be concerned with the physical and mechanical aspects of feeding mentally retarded children rather than with metabolic problems such as phenylketonuria. My usual approach to an audience is to ask a lot of questions to try to intimidate them, but I will forego that pleasure this morning since I am moderating rather than lecturing.

Perhaps I should simply introduce the speakers and not be heard from again until I announce lunch. However, I am afraid I will have to interject myself from time to time since I represent the discipline of Dentistry, which is concerned with the problem to be discussed.

What are the problems associated with feeding mentally retarded children? We have all seen children with cerebral palsy who have trouble feeding themselves. These children show an obvious desire to feed themselves, just as they show desires to communicate and to join in activities with others. We would like to do something to accommodate their desires in self-feeding.

Conditions having feeding problems other than cerebral palsy include congenital amputees who must have devices to help them feed themselves; patients with cleft palates; and those with facial abnormalities and malocclusions. We would like to know what we can do for these patients. Our approach will be an interdisciplinary panel discussion including representatives from nursing, occupational therapy,

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*D.D.S., Program Director for Dentistry, Institute for the Study of Mental Retardation and Related Disabilities, The University of Michigan

physical therapy, speech and nutrition. We hope, with this approach, to delineate problems and give some direction in solving them.

I would now like to introduce Mrs. Ernestine Donnelly, who is the Chief Dietitian of the Plymouth State Home and Training School. She will discuss the importance of nutrition as related to the feeding problems encountered with mentally retarded children. Before turning the program over to Mrs. Donnelly, I would like to mention that from my own disciplinary standpoint there are concerns regarding the feeding problems of the mentally retarded. In the dental clinic we see children with some of the previously mentioned problems. Along with cerebral palsy and cleft palates we see malocclusions and food retention from misplaced teeth. Often we see cases in which the upper lip has curled making it inoperable in forming a seal. Consequently, the lower lip takes up this function. We also see tongue thrusting and we wonder if we can help these children back into a more normal state. Unfortunately, there are not enough good answers to solve all of these problems. For example, putting teeth back into occlusion may not solve mastication problems or improve speech. The problems do exist, and they need much more work; they are difficult, but not insoluble. I will now turn the program over to Mrs. Donnelly.

INTERDISCIPLINARY PANEL PRESENTATION:
SOLVING FEEDING PROBLEMS OF
MENTALLY RETARDED CHILDREN

NUTRITIONIST

Ernestine Donnelly*

As I have listened to the speakers preceeding me, I know those who are involved in feeding the mentally retarded are encouraged by the emphasis placed on the interdisciplinary approach to meet the needs of the retardate.

The group here today does not need a session in nutrition. I'm sure all of you have had this in your training. What you do need is an introduction to the problems of feeding the retarded. The dietitian or nutritionist, generally, does not meet with this situation in the general hospital field or in consultation.

Often, one of the deciding factors leading to the institutionalization of the retardate is the problem of feeding him. To the normal individual the process of eating is a routine one with the sucking, biting, chewing, swallowing reflexes merging one into another. Not so with the brain damaged individual. These reflexes may be intensively weakened. The natural anxiety for nutrition disorganizes these weaknesses even further. To the family of such an individual, feeding becomes a time of absolute frustration and chaos.

In some severely brain damaged individuals the swallowing reflex has been impaired to the point of almost non-existence. This group must be maintained through gastrostomies with tube feedings providing nutrition. Approximately twenty of the residents at Plymouth fall into this category.

In another group of residents, tube feeding through a naso-gastric tube provides nutrition while the resident fluctuates between progres-

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sion and regression. For no known reason these individuals stop eating for periods of time. Some have again resumed consuming normal consistencies of food after two years of being fed by tube.

In other individuals, not involved to the extent just discussed, well-meaning families, fearing the patient will starve, concoct a mixture of pureed foods thinned with milk. This is given to the patient in a nursing bottle. The long process of teaching the patient to eat is not even attempted.

Guilt feelings on the part of the parent may create a situation where the retardate cannot be denied "his one pleasure" and obesity results. Other retardates are "easier to live with" if they get what they want to eat. This sometimes ends up in bizarre, to say the least, meal patterns and questionable nutrition.

These are but a few of the feeding problems encountered in feeding the retarded individual. The list is endless. When institutionalization becomes necessary, the problems are not magically solved--merely passed on to the admitting facility. Here the care of the patient becomes an interdisciplinary one.

The discipline of nutrition reaches into many of the other disciplines. The first concern is that the resident or patient, whatever terminology preferred, receives adequate nutrition offered in a manner he is able to consume. The nutritionist or dietitian can plan all manners of diet as far as texture and consistency, but if the patient's needs are not satisfied it does little good.

If the resident has not learned to feed himself and is judged after medical and dental examinations to have the capacity to do so, then the occupational and/or physical therapy disciplines join the resident program to begin the sometimes interminable process of teaching the resident to feed himself. Nursing, psychology, speech, special education and recreation disciplines, at varying times, all enter into the total care of the resident in an institution such as Plymouth. In each discipline food is involved. As an example of how an institution such as Plymouth attempts to solve feeding problems of residents I will describe our approach.

Since no standards have been set for the nutritional requirements

of retardates, the Recommended Dietary Allowances are used with the diet offered in three consistencies. The menus used at Plymouth are developed from standardized menus planned by the Food Service Coordinator and Food Committee for the State of Michigan Department of Mental Health. Since we have a wide range of ages here, we must have a wide range of calories available also. The 1600 calorie or "single serving" category supplies the nutritional needs of the youngest group of residents. By raising serving sizes to single and a half, double, or even triple servings, the nutritional requirements are raised to fill the needs of the older population. We find it quite easy to adapt by sending out printed menus to the wards. These menus are posted in the feeding areas, and the amount of servings are controlled by specified serving equipment. These cycle menus change with the seasons. They are four weeks in duration with the first week repeated four times, and the second, third and fourth weeks repeated three times. This is how we base our caloric requirements.

As a Dietitian I found it hard to believe 50-60 residents required quadruple servings. These residents are actually eating this much food. They are the "string bean" type individuals which emphasizes the fact that one cannot always explain how the retardate utilizes food.

Chronological age is not an accurate basis for determining calorie needs. Younger patients, who are spastics and expend enormous amounts of caloric energy due to constant muscle spasms, may require double the amount of calories stated for their age group. Another resident may be of adult age chronologically, but may require the calories of a much younger age group or obesity will result.

Consistency of the diet to the retardate is as important as caloric requirements. A normal consistency of the diet, or "solid" as it is termed here, is consumed by 674 of our residents. An intermediate or "chopped" diet is necessary for 142 more. The "ground" consistency is prepared for 286 residents. One hundred and twenty of the approximately 1200 residents are on therapeutic diets.

With a centralized kitchen the next step after preparation is conveying the food to the resident areas. This is accomplished by

trucking 20-bulk food conveyors and equipment carts to eight different buildings. Ideally, Food Service should have personnel serving in each area. Since this is not possible at Plymouth, patient care personnel become part of the team providing nutrition for the resident. Menus posted in each serving area are accompanied by resident diet requirement sheets. Ward rounds are made routinely at mealtime by at least one of the dietitians.

Since the population at Plymouth is mostly children, much training is needed and is being carried on.

Constant training is needed for the attendants caring for the residents' nutrition. Unfortunately they will allow their personal likes and dislikes to enter into serving the residents. Though adequate food and balanced meals are distributed, constant checking must be made to ensure the residents are fed properly.

This is stressed in orientation to the new attendants employed. In a two hour period the dietitians at Plymouth try to present the meaning of good basic nutrition, ward feeding standards and sanitation in food handling. Ward rounds by the dietitian helps check actual serving in the ward situation.

A number of the programs have small groups seated away from the regular dining area. The purpose is to teach the residents the aesthetic and social experiences of a family style meal.

The Occupational Therapist and her assistants work with a small group of young residents in hopes of teaching them to eat properly and avert complications that may later necessitate these residents having to be fed. She has worked with programs and wards to set up a plan of feeding to enable the residents to become self-feeders.

With this presentation I hope I have made you aware of some of the problems encountered in feeding retardates in an institution. There is no magic formula to solve these problems overnight, and the challenge is a great one.

Feeding and nutrition of the retardate has too long been a hit or miss system. The retardate is a person, whether institutionalized or in the community. He needs help and understanding of his feeding

problems. It is well known that deprivation can increase the problems of retardation. As dietitians and nutritionists we need to recognize this very real area where our particular talents are needed and are applied to such a small degree.

INTERDISCIPLINARY PANEL PRESENTATION:
SOLVING FEEDING PROBLEMS OF
MENTALLY RETARDED CHILDREN

OCCUPATIONAL THERAPIST

Carole Hays*

In an attempt to solve feeding problems of the child with mental retardation, I believe that some of the concepts which emerged in the last few decades must be altered. Various departments were designed to carry out education, care, treatment and rehabilitation of the mentally retarded, and even though subsequent program needs of the children were different, each department was responsible for provision of specific services or programs to the child. Despite many positive written philosophies concerning the child, my concern is that each area was profession-centered rather than program and child-centered. In other words, it is often the institutional organization that is the center of things rather than the individual child. In order to plan and implement modern and meaningful programs, we must move away from departmental structure and work towards a meaningful interdisciplinary approach.

In implementing any feeding program with the child with mental retardation, it is essential that the child's developmental level be known. The occupational therapist needs to make an evaluation in collaboration with the rest of the team in the areas of physical development and posture, motor control abilities, social response and play activities, locomotion, manipulation, and speech and language skills. The techniques in teaching of skills in the child with mental retardation are chosen on the basis of this evaluation. I'd like to briefly review each of the methods of feeding that could be introduced

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to the child according to his readiness.

Feeding may be accomplished other than by mouth. The child may be so severely retarded that he cannot suck or swallow. This child is usually very unresponsive. Progress to the next area of feeding depends upon further maturation. In this case the food may be a formula prescribed by a physician or a nutritionist, either given by nasogastric tube or gastrostomy tube. During the feeding the child should be cuddled and talked to at intervals to promote his emotional developments. The position for this method of feeding the child is usually restrained and on his back with head elevated. After feeding, the restraint should be removed and the child cuddled. The equipment involved would need to be that necessary for tube feeding or gastrostomy feeding.

The next step is usually feeding by mouth. The physical signs of readiness would include the child's ability to swallow his own saliva and the presence of a lip reflex. The formula may be prescribed by the physician or a nutritionist and usually a bottle with a nipple with enlarged holes is used or sometimes spoon feeding may be initiated. At this phase the child is held in a semi-reclining position. If the child is too large to be held, he should be positioned in a semi-reclined position with the body supported.

The next step would be sucking and swallowing. At this stage the child is able to suck his fingers or an object. He may be able to pull liquids from a bottle by a pressing action rather than true sucking. He can swallow saliva or water without difficulty. The prescribed formula is offered and the feedings may gradually be thickened. The position again would be semi-reclining, either held, or in a reclining type chair.

The next step would be spoon feeding. At this stage the child is able to swallow formula easily, can swallow thickened formula from the bottle, can open his mouth when a spoon touches it, and closes his lips on the spoon. The tongue may project as the spoon is withdrawn. He is able to manipulate the food in his mouth, but still often chokes at times during the feeding process. The type of food preferable at this stage is strained or pureed food. During this stage the child's

hand to mouth activities should be encouraged and the food should be placed where he can put fingers in it while being fed. His messiness should be accepted. The child should be told that he is eating. The type of equipment that is useful at this stage is an apron for the child and the mother or mother substitute. It helps many times if the plate is anchored with a suction cup on the bottom. The chair should be such that he is able to keep good anatomical position with his feet on the ground. If the child wants to start handling his food, the spoon may need to have a slight bend in it to make feeding easier, or sometimes it is necessary to enlarge the handle by wrapping it or using a spoon with a large handle.

The next step is cup feeding. At this stage the child can suck and can nurse the rim of the cup. By six months developmental level, the child may put his hands on the cup and begins to put the lips over the cup but chokes often. The child will anticipate the cup with head reaching and mouth opening. The child should be praised for his efforts when holding the cup and he should be told that he is drinking. The adaptive equipment that is sometimes used at this stage is a weighted cup with a lid which is sometimes helpful, but not always essential.

The next step children usually come to is finger foods. At this stage, readiness is shown by ability to munch rather than suck, showing eagerness or fussiness if the mother or mother substitute is slow in presenting food, poking with index finger at the nipple or at food in the dish, and grasping the objects with thumb and finger opposition. The child is able to swallow small amounts of food and can move food into the chewing position. Finger foods should have taste, texture and color appeal. For example: green beans, carrots, celery sticks, apple slices, seedless grapes, bananas, meatballs, small potatoes, scrambled eggs, small sandwiches, crackers, etc. With some children you might have to teach them to chew by moving the jaws up and down. You must also be careful at this stage that they do not stuff their mouth without swallowing. Equipment necessary for finger foods is a well-fitting table and chair so that the child is comfortable and has correct posture while eating.

The next step is spoon feeding. Signs of readiness are that the child finger feeds all pieces of food from the tray, rubs spoon back and forth, is able to turn pages in a book, can build a tower of two blocks, and can handle and release objects. Initially, it is important that the food selected is something that easily adheres to the spoon such as squash, mashed potatoes, oatmeal, puddings, etc. If possible the child should use a straight handled spoon. The adaptive equipment might include a plate with a raised edge and stabilized with a suction cup base.

The next step would be using a cup and a glass. At this stage he should be able to eat with a spoon or starting to do so. He should swallow, not suck liquids. The only equipment that is necessary in this stage is a weighted cup or glass. One that is inexpensive is a small flexible type plastic tumbler.

In planning the program, the therapist must be aware of the fact that learning is basically sequential and that the chronological age of the child with mental retardation is not as important as most of the steps mentioned above. The child with mental retardation is in need of systematic habit training. I must warn you that each step will be slow and that repetition is important. Breaking a complex task into small steps, providing a setting where the child can successfully perform the act and rewarding immediately with praise the correct response will increase learning. The child also learns much by mimicry as well as practice.

The elements that I see as essential in solving feeding problems include evaluating the child with mental retardation, planning a program in cooperation with the nursing staff, physical therapy department, speech pathologists, nutritionists, and the family based on the child's developmental level, providing the child with a chance to do the repetitive activity and rewarding correct responses. Addition of adaptive equipment for the individual needs of the child should be used at a minimum when at all possible. The addition of complicated adapted equipment to this type of child at times causes more difficulties than assistance. The more basic the equipment the greater the opportunity for carry-over by the staff and the family.

The other thing I'd like to mention briefly is the use of behavior modification techniques in the training of retarded children. Many hospitals do use the reward system for praising positive behavior and often the rewards are food items such as M & M's, ice cream, and sugar candies. Although the behavior modification approach has been proved as being successful in some circumstances, I again want to emphasize the need for coordination between those people using the behavior modification reward system and the nutritionist on the staff. If candy does seem to be the item that works the most successfully with the child, then I think those individuals that are experts in the field of nutrition should help us in planning the amount and kind of reward that would be the safest nutritionally and not encourage obesity or substitution of the reward in place of an adequate diet.

In conclusion, I again would like to emphasize the importance of the evaluation of the child's developmental level, the coordination of the interdisciplinary team, and the proper handling of the reward system and behavior modification are all necessary ingredients in a successful feeding program for a child with mental retardation.

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INTERDISCIPLINARY PANEL PRESENTATION: SOLVING FEEDING PROBLEMS OF MENTALLY RETARDED CHILDREN

PHYSICAL THERAPIST

Leila Green*

Not long ago we had a staffing conference with a consulting child psychiatrist about a bright four year old boy with cerebral palsy, because his behavior was puzzling to the staff. The boy was not observed by the psychiatrist prior to or during the conference. His nursery school and special education teachers, a social worker, and I simply reported to the psychiatrist on his behavior. Each of us saw him through different eyes, from a different professional set. Each had observed different behavior in the several settings. We were all concerned personally that we might fail in helping this boy; we were willing to admit that we had observed behavior which we did not know how to modify and which seemed to interfere with the accomplishment of our treatment goals. We sought expert advice, not so we could become psychiatrists, but so we might more adequately apply our professional training in working with the boy.

The parallel of that story is taking place today. The developers of this program have said, in essence, that:

> Many mentally retarded children do have feeding problems.
> As nutritionists, you are responsible for providing the mentally retarded with proper nourishment.
> As nutritionists you share the task of feeding the nourishment to the child.
> Your (and my) professional training may not have adequately prepared you to work with children with severe feeding problems.
> The occupational and physical therapists have worked with

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the multiply handicapped child in the past.
Therefore, let's ask them to join the nutritionists in addressing ourselves to the feeding problems of mentally retarded children.

It is a privilege and a pleasure to represent the physical therapist on the panel. I shall not try to sell you the idea that we have the answer, nor will it be possible to make each individual in the audience an "instant" physical therapist. However, I shall try to:

help you view the disabilities of the mentally retarded from a physical point of view;
help you gain insight into some of the prerequisite skills needed for feeding skills;
have you feel what it is like to do some very normal things in an abnormal way;
give you a thumb-nail sketch of the role of the physical therapist in the field of mental retardation.

I have followed the philosophy of Galileo who said you cannot teach a man anything, you can only help him to find it within himself. As a "normal" adult you breathe, feed yourself, suck, chew, swallow, cough when you swallow food "down the wrong throat" and manage a variety of food with ease. By studying what you do and how you do it during the eating process, then observing the mentally retarded child, you can build knowledge and understanding from your own experiences. Skill in feeding the multiply handicapped mentally retarded child will come with practice.

Years ago, before we learned the errors of our ways, therapists were prone to segmentalize the patient - the physical therapist took the lower extremities that are needed for walking, the occupational therapist took the arms, the speech therapist was given the head and neck to work with. Now we like to think that each person who is in contact with the patient is working with the whole patient, being ever mindful of his total needs. Living in a society is not just walking about with a nearly normal gait pattern or combing one's own hair or asking for another glass of milk; living is doing all of these things and more. As health workers began working more closely with each other we found we had to shed much of our professional jargon so we

could better communicate with each other. In spite of the emergence from being just the "lower extremity specialist", physical therapists still are primarily concerned with the patient's ability to move in his environment. The concern must be not only the development of necessary prerequisite skills, but also for those aspects of the child's disability which prevent or retard the development of the skills.

To be more specific, I have put on the board some of the very broad goals of physical therapy that apply in the field of mental retardation:

1. Prevention or alleviation of contractures and deformities.
2. Improvement or maintenance of muscle strength, range of joint motion, endurance and coordination.
3. Development of the highest level of functional skills possible.
4. Development of better breathing patterns.

The first goal is very important and is the responsibility of not only physical therapists, but of everyone who works with children. Although not all deformities can be prevented in a population of severely physically handicapped mentally retarded children, many can be avoided in the very young child. The effect of contractures and deformities can be devastating to the child's chances of gaining the postures, movement patterns and skills necessary for self-care. Just prior to the feeding demonstration this morning we will show some slides of terribly deformed patients - not just to shock you, but to call your attention to the fact that deformities can and do develop unless there is a vigilant preventative program. Keep in mind, as you look at the slides that eating in the normal fashion would be unlikely in many of these patients not because they are mentally retarded, lack motivation, and so on, but because of the physical problems.

Even if one can prevent deformities, it is necessary to develop the muscle power and the range of movement necessary for a motor skill. For example, one needs a certain amount of strength, coordination and

range of movement to sit in a chair, as at dinner time, reach for a spoon, gather some food on the spoon, move the spoon and food to the mouth, get them into the mouth, chew and swallow it. One also needs to be able to repeat this procedure over and over (endurance) while maintaining balance in sitting for the length of time needed to finish the meal.

Ideally, all children would become independent in all self-care skills, but in reality some children just cannot develop that far. What we can attempt, however, is to help the child to attain the prerequisite skills much as they develop in the maturing child. A child becomes skillful in raising his head when lying on his stomach before he can sit up alone; he sits alone on the floor before he can walk alone, etc. It is very important that those of us working with a child who is mentally retarded keep in mind where the child is now in the development of prerequisite skills and where he is going next - a 67 year old patient learned to feed herself in a few months time after all those years of infantilization. She had, in fact, the prerequisite skills and very strong motivation to be independent, but the care contact staff had always fed her because it was faster, perhaps.

The last goal is applied to the children with cerebral palsy more than to any other group of mentally retarded. No one can witness a patient choking on foods without experiencing some anxiety; normal adults have been known to choke to death on a piece of filet mignon. Chewing, sucking, swallowing and breathing are normally coordinated so choking is a rare happening. The child with cerebral palsy or other neurological dysfunction may not have the coordination needed to eat and breathe without mishap.

The focus on the child with cerebral palsy is intentional, for they comprise the largest single diagnostic group that physical therapists work with in centers for mentally retarded children. (Whether the child's official diagnosis is cerebral palsy or not, we grouped the children into this category if they had "spastic" or "athetoid" characteristics.) The parents of a young cerebral palsied child often recognize that something is wrong and seek medical advice - they may

describe the difficulty as "stiffness" or "floppiness" or "can't raise his head up or sit." The cerebral palsied child does not move normally and doesn't reach the developmental milestones when he should. The spastic is stiff, does not move very much or does so quite abnormally; he is very prone to crippling deformities. Muscles are in imbalance because the spastic muscles far outpull the opposing muscle groups. He does not develop strength in all muscle groups as he should, he loses joint range of motion as a result, and thereby loses the potential for functional skills. A very typical pattern in moderately and severely spastic children is excessive flexion of the elbows and tightness of the shoulders - a combination of difficulties that makes self-feeding a problem. Hands are often tightly fisted which can make grasping a spoon rather hard to do.

The athetoid child, another type of cerebral palsy, moves too much and cannot fix in a stable posture. His head wobbles about, his limbs flail in an uncontrolled manner, his tongue is too mobile and uncoordinated and his breathing pattern is often very faulty. Again, the combination of disabilities can lead to severe feeding problems.

The nice part of being "normal" and an intelligent adult is that one is truly a walking laboratory. There are a few things I'd like you to do. Take the question of coordination of breathing and swallowing: if each of you will begin to take in a breath and then somewhere in the process, swallow. What happens? You stop breathing, don't you? You have to interrupt the breathing pattern when you swallow. Now, try it when you already have a lot of air, as if you were going to speak. Let some air out, then swallow. What happens? You had to stop breathing again. This time, swallow a few times as you hold onto your larynx. What happens? The larynx moves forward and upward. This is to allow the larynx to butt up against the glottis so that when you swallow the contents go into the esophagus and into your stomach rather than into your lungs. If the structures themselves are not free to move, one has difficulty in preventing "inhaling" foods.

Another chore -- if you will please tilt your head backward, look at the ceiling and then swallow. Have you ever had to do this in the

dentist's chair? Did you have trouble in swallowing? Most people do. How many times, in grossly retarded multiply handicapped, institutionalized children have you seen the head tilted back and food poured in? The 67 year old patient mentioned earlier had been fed this way for years and years.

This time try to swallow with your mouth open and not moving your tongue. Most of the time we close the mouth and lips when swallowing, and the tongue is quite active inside of the mouth. The sucking pattern also requires lip closure around the straw or glass and an active tongue.

To summarize so far - a faulty head position, the inability to close the lips, the incoordination of the tongue and the inability to shut off the pathway to the lungs can contribute to feeding problems. Solving the existing and potential feeding problems can be a life-saving procedure. A Feeding Clinic was developed a few years ago at Central Wisconsin Colony and Training School in Madison, Wisconsin; it was an attempt to identify and solve feeding problems among the population of the Colony and to teach the ward personnel good techniques of food handling, feeding the children and developing higher levels of self-care skills whenever possible. One physician served as the motivating force to get the Clinic started - he had been called in quite a few times to give emergency treatment for a child who had aspirated food. The Clinic team included nutritionists, nursing staff, occupational therapists and others (such as physical therapists) on a consulting basis. A paper describing the Clinic is in Vol. 1, No. 2 of the JOURNAL OF CONTINUING EDUCATION IN NURSING, (July, 1970). The article might prove useful for those of you who are working with institutionalized children.

In addition to the position of the head and the motor patterns of the structures about the mouth, other factors can contribute to better feeding skills. I have listed on the board some of the positions in which people are fed or feed themselves. Eating while lying flat on your back is indeed difficult, yet by raising the head swallowing becomes easier. Normal children frequently eat snacks when lying prone

(on the stomach), watching television - again, the head is raised. The Romans reportedly ate sumptuous meals when lying on their sides, propping on one elbow. The most usual position for feeding is in the sitting position - the infant is held in a semi-sitting position on the parent's lap, the older child graduates to a high-chair, then to a regular chair. A quick look at the anatomy of the digestive tract points up the fact that sitting upright has advantages over the other positions.

What can be done with the youngster who, because of deformities, lack of sufficient strength or endurance, or for other reasons, cannot be fed in a sitting position? Obviously, some adaptation has to be made. The physical therapist often will concentrate on <u>preventing</u> contractures and deformities, especially in the younger child; if the deformities are "fixed" in the older patient, orthopedic surgery may be the only solution to getting the patient in a good, functional position for feeding. For the children who have insufficient strength to maintain a sitting posture, the therapist should work with the child and the ward staff toward developing greater strength and balance. One of the greatest lessons learned in the three years I spent at the Colony was that the ward personnel must be given the knowledge and skills necessary to supplement and complement the therapy programs -- of all the people working with the child, the on-ward staff probably effected the greatest change in the children. Once these staff members understood the nature of the problems and the importance of the role that the staff played, teaching them the skills was relatively easy. It took time, but was worth almost every minute spent. The same is true with parents of children who are still living at home; the child may spend five or six hours a week in therapy and the rest of the time at home. Why <u>not</u> show the parents how to pick up, bathe, feed, play with, cuddle, stimulate to move, position for naps, etc. their handicapped child? We don't ask them to carry out a long and arduous treatment program - just to handle the child therapeutically during the everyday activities that must be done anyway. Not all parents can and will assume this role, but the vast majority will

and do. The most difficult group to reach in an institution, is the "old timer" who has been doing things wrong for years and isn't about to change.

Perhaps one of the most useful tools in teaching either the natural parents or ward personnel how to handle the child is the concept of "prerequisite skills"; walking, for example, is a complicated and coordinated skill that begins to develop in the infant when he begins to raise his head when prone. Think of the host of major and minor motor triumphs that occur between birth and the first year of life--when most children begin to toddle about. By reaching the intermediate milestones one by one, the parents can better understand what we are trying to accomplish.

In closing, each of us has a responsibility to the child with mental retardation to help him develop the highest level of independence possible. Article II of the Declaration of General and Specific Rights of the Mentally Retarded, adopted by the Fourth International Congress of the International League of Societies for the Mentally Handicapped in Jerusalem in October, 1968, states:

> "The mentally retarded person has a right to proper medical care and physical restoration and to such education, training, rehabilitation and guidance as will enable him to develop his ability and potential to the fullest possible extent no matter how severe his degree of disability. No mentally handicapped person should be deprived of such services by reasons of cost involved."

This is a tremendous ideal; hopefully it can be reached. The final statement of the Declaration reads, "Above all, the mentally retarded person has the right to respect." Self-respect, and some measure of independence, are also very, very important to the retarded; we must help them reach toward these goals. Thank you.

INTERDISCIPLINARY PANEL PRESENTATION: SOLVING FEEDING PROBLEMS OF MENTALLY RETARDED CHILDREN

NURSE

Evelyn Provitt*

We have heard the presentations of our distinguished panel members. My first reaction is that a great deal of very important knowledge has been put forth. The question remains: How do we disseminate information to those individuals who are directly involved, disseminate information to those individuals who are directly involved, responsible for, and concerned with the care of the mentally retarded?

I am thinking about the mother who has a mentally retarded child at home; those in the community who give of themselves by taking in mentally retarded children who cannot return to their natural homes; those persons in clinical and state settings, such as institutions for the mentally retarded; and those who are in community agencies who come in direct contact, daily, with the mentally retarded. How do we disseminate information to these people? The problem of implementing approaches to feeding which will insure, develop, and maintain nutritional welfare for mentally retarded individuals may be solved by interdisciplinary training of ward personnel as mentioned by Mrs. Donnelly.

When we talk of mental retardation and the range of problems involved in developing maximum capability, we must remember that eating, and its correlative techniques and skills are very important. They become, in many of our settings, one of the primary problems encountered in the daily care of mentally retarded individuals. I will again pose the question; How do we get this morning's information to persons who are directly confronted with the problem? We cannot include ourselves among those having initial contact. I do not mean

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to say that the nutritionist, dietitian, physical therapist, occupational therapist, and the nurse are not in this primary group. But the day-to-day care of the mentally retarded is largely the responsibility of another group of individuals.

I was asked to deal with the role of the nurse in my comments. I guess I am rebelling against that because my considerations go beyond the role of one person. There is no question, as far as I am concerned, that the nurse is a very important person in an interdisciplinary team of programming treatment and care for the mentally retarded, particularly during an intensive habilitative training program. The nurse has a very important role within the context of attaining optimal self-care in the retarded individual.

The total number of identified mentally retarded persons in Michigan is 240,000. Of that total population only 4% are in state residential facilities. The rest are in the community in various settings. Many are in public or special education programs, many are in community vocational training programs, and many are sitting at home without a program and receiving no specific care. Of the institutionalized 4%, 1,375 are adults. The next largest number are those children and adults who are profoundly retarded and who have not developed their potential level of self-care skills to take care of their basic daily needs. I share this with you because I think it is important that what has been said, specifically Miss Green's outline of goals in the development of feeding, is just as important in communities outside state institutions as it is inside. Each of you, in your particular work setting, should insist upon a focus on nutrition and mental retardation. The importance of nutrition, whether in university settings or community service organizations; whether you are in direct or indirect contact, must be realized. What can each of you do to facilitate and further the dissemination of information and the development of community education for mothers, foster mothers, and staff in diagnostic clinics who often are the first to come in contact with mental retardation? This also applies to the school nurse, teacher, the public health nurse, etc. in a school setting.

I am concerned with points Mrs. Donnelly discussed, but they go

beyond just ward personnel. It is important to recognize, as we attempt to develop program objectives necessary to these goals, that up to now the "shot gun approach", and the "stop gap measure" have predominated over the implementation of a program concept on a 24-hour basis. Residential personnel, nurses, and mothers need home training programs. We can have the best programs, carefully structured with professional expertise, to deal with feeding problems of the retarded. Unless there is carry over, the program fails. Here again the nurse plays a crucial part. (I said earlier I was a little bit rebellious about focusing on the nurse's role because I am thinking of the nurse, the aide, etc. For purposes of discussion, I will include all of these as "nurses".) I hope that as we react to the whole conference and its information, we will recognize that the crux of solving feeding problems involves more of a focus on prevention. I think our state institutions, state agencies, educational institutions, community agencies, and the health field in general have <u>failed</u> because they have not paid the necessary attention to primary prevention. We find ourselves confronted with problems that have grown to the point of creating institutions. Many children are institutionalized because the family cannot identify and handle their disabilities, the basic problem being feeding. This means getting the child to eat, gain, and attain good nutritional status. Feeding problems demand attention and time from resident care staff: dietitians and other persons concerned with the daily living of the residents.

In attacking mental retardation, one of the problems we face in the clinical setting is the shortage of trained personnel such as the physical therapist, the occupational therapist, the dietitian, the dentist, and the speech pathologist. In the area of manpower development, this <u>must</u> be recognized as a major problem. Developing the kinds of manpower needed to implement the kinds of approaches that have been so well discussed this morning must be furthered. Thank you.

INTERDISCIPLINARY PANEL PRESENTATION
SOLVING FEEDING PROBLEMS OF
MENTALLY RETARDED CHILDREN

SPEECH PATHOLOGIST

Lawrence J. Turton*

The speech activities of the cranio-oro-facial region are frequently described as "overlaid functions" relative to the biological vegetative activities of this part of the body. (Black and Irwin, 1969) Speech has been considered to be secondary to the biological functions of chewing, swallowing and breathing and dependent upon them for development. Consequently, clinical programs for certain speech disorders have included non-speech exercises of blowing, chewing and feeding as a prerequisite for speech activities. (Westlake and Rutherford, 1961; Hanneman, 1970; Berry and Eisenson, 1956) The assumption underlying the inclusion of these non-speech activities is that strengthening the musculature or creating awareness of structures will facilitate speech improvement. Unfortunately, virtually no experimental evidence has been offered to support this clinical assumption.

Sufficient evidence does exist, however, to suggest that biological activities of the cranio-oro-facial region do not necessarily facilitate the development of speech activities. In clinical terms, the evidence suggests that the most effective and expedient way to improve a child's speech is to teach him to talk. Feeding sequences and activities are undoubtedly necessary for the child's well being and health and may have important social consequences; but their relevance to speech behavior is questionable and may be an inefficient use of the speech therapist's time. (Shelton, 1963)

The understanding of articulation development for speech has

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changed significantly in the past decade and raises serious questions regarding speech and non-speech activities. Although initial concepts of sound development viewed the process as being primarily a motor learning task, recent writings point to the fact that the motor learning is a basic but minimal aspect of sound development. The acquisition of the phonological system, i.e., the way the sounds are used systematically in language is of much more importance during the developmental years. (Crocker, 1969; Winitz, 1969) When motor learning was viewed as the end-product of the acquisition phase, defects in the articulation process were viewed as primarily motor problems and remedial procedures were motor-oriented. (Berry and Eisenson, 1956)

The evidence for the motor-oriented viewpoint of articulation development is open to serious question. The motor aspects of articulation behavior are learned within the first thirty months of life by normal children (Winitz, 1969) who are producing virtually all of the sounds of the language by thirty-six months of age. The motor aspect of articulation learning is only the initial stage of the process. Acquiring the phonological rules of the language, i.e., the process for combining and arranging sound features, is the critical phase of articulation learning. (Crocker, 1969) The child is not learning just the motor movements required for articulation; he is learning to use a systematic set of sounds.

The assumption that children with articulation errors have motor problems has led to a long series of studies which attempt to single out the specific motor deficit related to articulation problems. These studies have been reviewed comprehensively by Winitz (1965). He concluded that:

> "In general, the studies do not indicate that articulatory defectives are retarded in any specific measure of general motor ability. Sufficient evidence is also lacking to support the hypothesis that articulatory defectives demonstrate a general retardation in motor skills." (Winitz, 1969, p. 155)

In most studies of articulatory defectives, motor movements

involving speech are below normal but non-speech oral movements and other motor systems are rarely deficient unless there is a specific underlying physiological problem. This suggests that different control mechanisms are probably present in the central nervous system (Hixon and Hardy, 1964) for speech and non-speech activities. In another paper (Turton, In Press), I have suggested that close evaluation of the responses of the articulatory-defective child often reveals that the child is able to produce the error sounds in another context or as a substitute for another sound. That is, the sound may not be used correctly in the system, but the motor movements are present in that the sound is present in the child's speech.

Another direction in research has been the evaluation of the manner of functioning of cranio-oro-facial structures during speech and non-speech activities. This research casts significant doubt upon the relationship of these two human behaviors and the clinical basis for non-speech exercises including feeding. Moll (1965) has provided cinefluorographic evidence that the pattern of velo-pharyngeal closure for speech is different than that for blowing and swallowing. During blowing, some individuals utilize tongue valving or buccal functioning to provide pressure. On the other hand, all evidence on the articulatory movements of the velo-pharyngeal sphincter demonstrates that it needs to be present during speech. No clinical or experimental evidence appears to exist to justify including blowing or sucking exercises in a speech program. The mere fact that children who have been exposed to blowing and sucking continue to need speech therapy is probably the most cogent critique of this approach.

Articulation behavior, when described in relationship to feeding activities, is considered to be a static form of behavior controlled in the same way by the central nervous system as are non-speech activities. Again, recent evidence suggests that this assumption is also open to question. Hixon and Hardy (1964) have suggested that a network of neurological components at all levels of the central nervous system may be responsible for articulation functioning. Hardy (1970), after reviewing the literature on neural control of speech, argues that:

> "...even in the presence of some type of abnormality of the neuromuscular system, the speech-generating neuromuscular process is uniquely organized and is dissimilar from such processes that underlie movements of the same muscle groups during other acts." (p. 60)

It would appear to be highly unlikely that non-speech activities would facilitate the development of neural patterns to control speech.

Non-speech activities are often included in a speech therapy program because they increase awareness of the oral structures. (Berry and Eisenson, 1956) Although the study of oral perception is relatively new, the data indicate that the development of the perceptual system within the oral cavity may be completed at a different rate than is the phonological system. (McDonald and Augnst, 1967; Ringel, 1970) One tentative conclusion is that the sound system is acquired prior to the stabilization of the oral perceptual system. One inference may be that the human organism may need to perceive speech movements independent of movements required for other activities. Shelton, Hahn, and Morris (1968) state that there is no evidence that exercises for developing awareness or oral sensation have any effect whatsoever upon speech. Shelton and his associates (1970) have demonstrated that it is possible to teach voluntary palatal movements despite the lack of awareness by the subject regarding the movement or degree of movement.

The argument can be raised, of course, that for neurologically or structurally impaired individuals, vegetative activities such as feeding are critical for them in the acquisition of speech. In order to accept this argument, however, evidence would have to be brought forth to demonstrate that:

1) They learn a set of sound systems or movements different from non-impaired speakers;

2) They all have the same or highly similar articulation deficits;

3) They have different sensory or neural patterns of control for speech;

4) They do improve their speech on the basis of feeding or other forms or vegetative activity training.

Until such evidence is produced, I would like to offer the following restatement of the relationship between speech and feeding activities.

Speech and vegetative activities are produced by the same structures. However, speech is no more an "overlaid function" of the mouth and related structures than are writing and piano playing "overlaid function" of the fingers. Both feeding and speech are normal, expected functions of the human species. Feeding procedures have important roles to play in the life of the handicapped child including his health, acceptability to others, improvements of independence characteristics, and possibly social interaction with others. Feeding movements, in light of available evidence, cannot be said to influence articulatory movements needed for speech. Obviously, if evidence to the contrary is produced, this last statement will have to be revised. In terms of efficient use of professional time, the speech therapist should reserve the development of feeding programs and activities for those disciplines which are best trained and equipped to implement such programs. The speech therapist should assist the other disciplines in the improvement of the social-communication aspects of mealtimes and special feeding programs.

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DENTIST-MODERATOR

Henry Kanar

I was interested in the things that were brought out. I think we have all seen again the need to individualize for the particular child rather than group them in large categories. The concept of individualizing the consistency of the diet and the caloric intake for the children's specific needs is an important one. Mrs. Donnelly also brought out the need for interdisciplinary functioning in this area.

The gradual progress of a child through the various stages from sucking to chewing, as emphasized by Miss Hays, is important to me as a dentist. If a child remains on a liquid or pureed diet and is capable of progressing, we may have reinforced a visceral or primitive sucking pattern, and contributed to tongue thrusting and malocclusion. Naturally, we would like to see them graduate toward a diet of more normal consistency so they can chew, exercise, and approach normal occlusion.

There is also the matter of M&M's in behavior modification. I do not want to harp on this too much, but it used to be of great concern to us. We would tell children not to snack too much, only to have them return to their behavior modification programs and be liberally given M&M's. At times we are not as coordinated as we would like. At the same time, if behavior modification does bring about more normal feeding, it is our responsibility to correct any difficulties resulting from the ingestion of too much refined sugar. The water supply of the Plymouth State Home has been flouridated to help overcome the effects of a diet containing large amounts of such sugars.

I am happy that the audience was not too proficient in following the instructions of Miss Green on atypical swallowing patterns: otherwise, I expect a mass attack of coughing that probably would have concluded the program for this morning. The goals she outlined are ones

we all, regardless of discipline, should keep in mind.

Thank you, Miss Provitt, for redirecting our focus into the community, which is where the bulk of these children reside.

Dr. Turton delineated the areas in which speech and the vegetative functions of feeding diverge. I would tend to agree that certain functions have to be separated. Thinking back over some clinical experiences, the child who grinds his teeth is not necessarily capable of masticating food correctly. From strictly a mechanical standpoint, in that instance, we see a divergence in functioning.

We have time for one or two questions. If you have a question and would like to direct it to a particular panelist, please do so.

QUESTIONS & ANSWERS
FOLLOWING PANEL PRESENTATION

1. Q: Would it be possible and beneficial to instruct the mother on methods of feeding her children?

   A: (Mrs. Donnelly) This would be a great help. Some parents are interested enough to come in and we do talk to them. Others are too emotionally involved and they don't want to bother. If the children are on a particular type of feeding program this break in the pattern can regress the child to the point that we have to start over again.

2. Q: How difficult is it for the physical therapist to accommodate disabilities if the child has been living at home rather than under care in a residential facility?

   A: (Miss Green) It depends on several factors. If the child is presented with fixed deformities, one must be careful in dealing with the parents so their guilt feelings are not further amplified. In many ways it is easier for the therapist to work through the natural parents than through institution staff - the parents have a natural bond with the child. Most experts in the field of mental retardation agree that the child is better off at <u>home</u> than in an institution, provided he gets reasonable care. The trend, at least at Central Wisconsin Colony, is to place as many institutionalized children outside of the Colony as possible, and to urge the parents to care for the child at home as long as possible. Every effort is made to assist the parents to obtain the needed services for the child in the home community.

NUTRITIONISTS IN UNIVERSITY AFFILIATED CENTERS: A NEW BREED

Ninfa Saturnino Springer*

During the 1970 National Workshop (1) for Chief Nutritionists of University Affiliated Centers (UAC), one could perceive emerging a new breed of questioning, community-conscious nutritionists. Not limiting themselves to their specialties, these nutritionists are endeavoring to learn more about other disciplines. Thus, they make themselves knowledgeable and conversant in subjects other than those for which they are professionally prepared. Like our youth of today, this new breed is more rebellious and less ready to accept the usual. Carrying the scepter of leadership, this new type is characteristically the developer, planner and dreamer in contrast to remaining strictly "task oriented." This paper is divided into three parts. A brief history of the University Affiliated Centers is followed by an overview of the interdisciplinary model which is offered as an illustration of a new trend in nutritionist activities. The last section presents the results of a recent survey which was conducted to determine the various activities of nutritionists involved in a University Affiliated Center setting.

A BRIEF HISTORY OF THE UNIVERSITY AFFILIATED CENTERS

University Affiliated Centers grew out of a need for more professionally trained individuals to undertake research and training in the field of mental retardation. The establishment of training centers was a major recommendation of the President's Panel on Mental Retardation (2). On October 16, 1962, after one year of deliberation, the twenty-eight member Panel submitted their report to President Kennedy. In a message to Congress on February 5, 1963, President Kennedy reiterated this need and called for remedial legislation to "...seek out

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the causes of mental retardation and eradicate them...strengthen the underlying resources of knowledge and, above all, of skilled manpower which are necessary to mount and sustain our attack on mental disability..."

The White House called a conference on mental retardation from September 18 to 20, 1963 to which four hundred people from across the United States were invited to orient, stimulate, and share problems associated with mental retardation (3). Successfully climaxing this series of events was the passage of amendments to the Social Security Act. A new and comprehensive medical care program was designed to meet growing maternal and child health problems in urban areas. Title V, Section 511 of the Social Security Act (4) authorizes grants "for training personnel in health care and related services for mothers and children, particularly mentally retarded children and children with multiple handicaps." These training grants were made to public and non-profit private institutions, with preference to those with an affiliated hospital or a medical school. The ultimate goal of University Affiliated Centers is to combat mental retardation through (a) training of specialized personnel to work in the many disciplines concerned with mental retardation, (b) services and treatment centered on helping each retardate attain his highest potential, and (c) research which concerns itself with training and service.

INTERDISCIPLINARY TRAINING

One of the program priorities of the UAC is to develop an interdisciplinary model for the study of problems and the training of manpower in mental retardation. The problems in mental retardation are unique and complex, and the use of more than two disciplines in striving towards problem solutions is most appropriate. According to Luzski (5), an interdisciplinary team "is a group of persons who are trained in the use of different tools and concepts and among whom there is an organized division of labor, around a common problem with each member using his own tools." The Mental Retardation Training Program at Ohio State University has formulated its own definition which states that "an interdisciplinary approach is taken to mean two or

more professional disciplines coming together as a team of equals in comprehensive care management." Equality of the team members is an essential feature of an interdisciplinary setting. In one center the program in nutrition was not allowed to develop further until the occupational therapy program had reached a similar level of program development. A team of co-equals, however, does need leadership; a member is assigned regardless of status or prestige of one discipline. Cruickshank (6) states that "position in the interdisciplinary structure is of little import; each discipline uses its skills of the moment in the best possible way to seek solutions to the problem before it. The leadership role is not defined by historical prerogatives, regulation, or law...but by pertinence of the discipline to the agenda before the team and by the capacity of the individual representing that discipline to weld the other members...."

Achieving a stage of true collaboration between the disciplines cannot be forced. There should be a feeling of need for a discipline in the solution of existing problems. On the other hand, to be ready for interdisciplinary collaboration, the discipline involved must have arrived at a certain degree of sophistication. Immaturity or insecurity may force a member to retreat into his own discipline. The development of an effective method of communication or a "neutral terminology", instead of using the special jargon of each particular discipline, may weld the disciplines together.

The characteristics most emphatically desired in interdisciplinary workers are personal and professional security, emotional maturity, flexibility, humility, and open-mindedness. It is desirable that staff should be discovery-minded and program-oriented, rather than status-minded and reward-oriented.

Students trained in this setting may become two types of interdisciplinarians. One type is represented by the person who combines, within himself, the skills and abilities of two or more disciplines, while another is the person with sound training in one field plus enough understanding of other fields to provide a basis for effective collaboration. Both types are needed, and, once these qualities are attained, the model, as Cruickshank (6) puts it, may be likened to an

orchestra with a soloist taking up the lead once in a while, or to a mural artist who blends the concepts of industry, religion, art, music, life, death, etc. in one beautiful canvas. Interdisciplinarians require "a mentality which can focus on the goal, but simultaneously is appreciative of all which goes on around it." It is in such a setting that UAC nutritionists have thrived and metamorphosized.

ACTIVITIES OF UAC NUTRITIONISTS

A survey was conducted to obtain information about the activities of University Affiliated Center nutritionists; the results are also intended to provide guidelines for future program planning.

Questionnaires, designed to determine the scope of nutritionists' activities in University Affiliated Centers, were mailed in February, 1970 to directors of the centers. Activities were listed under the headings: training, service, research, administration, and professional development. Respondents were requested to indicate the percentage of time, out of their total working hours per week, that they devote to each of these activity areas.

Only thirteen University Affiliated Centers have one or more nutritionists on their staff; these participated in the survey and are the following:

Center for Development and Learning
University of Alabama Medical Center

University Affiliated Project
Children's Hospital of Los Angeles

Child Development Center
University of Colorado Medical Center

University Affiliated Facility
Walter E. Fernald State School

Institute for the Study of Mental Retardation
and Related Disabilities
University of Michigan

Mental Retardation Center
New York Medical College

Division of Disorders of Development and Learning
Child Development Institute
University of North Carolina

University Affiliated Facility Mental Retardation Unit
University of Cincinnati

Mental Retardation Training Program
Ohio State University

Crippled Children's Division
University of Oregon Medical School

Child Development Center
University of Tennessee

Clinical Training Unit
Child Development and Mental Retardation Center
University of Washington

Kennedy Laboratory
University of Wisconsin Medical Center

Of the twenty-three nutritionists who responded to this survey, thirteen of them are chief nutritionists and ten are staff nutritionists. Two chief and two staff nutritionists work only part-time. Table I, giving training and experience of the respondents, shows that all except two hold one or more master's degrees, and four have acquired Ph.D. degrees. Only two nutritionists are not registered dietitians. For all centers the minimum education requirement for chief nutritionist is a master's degree. University Affiliated Centers offering graduate degree programs recommend that the chief nutritionist hold a Ph.D. degree in addition to some years of experience. While this is most desirable it is not always tenable due to the dearth of nutritionists possessing this training. The position of chief nutritionist demands the ability to develop not only service and teaching programs in nutrition, but also research. An advanced degree is also desirable since, in an interdisciplinary setting, competence of the disciplinarian is most important. Although the length of experience of the respondents varies considerably, half of the chief nutritionists have ten or more years of experience.

Table 2 gives the range of time spent on a given activity by the

TABLE I Qualifications of Respondents

TRAINING AND EXPERIENCE	NUTRITIONIST CHIEF - STAFF
Highest Degree Obtained	
no.	no.
B.S.	2
M.Ed.	1
M.A.	1
M.S.	5 3
M.P.H.	2 2
M.A. M.P.H.	1
M.S. M.P.H.	1 1
Ph.D.	4
Length of Experience	
yrs.	
5 or less	4 5
6 - 10	2 1
11 - 15	6 1
16 and up	1 3

respondents grouped according to whether they are chief or staff nutritionists, on part or full-time employment. Service activities include both clinical duties and consultation with agencies or organizations on the community or state levels. In a clinic, the nutritionist is involved in obtaining dietary history and evaluation of dietary practices and intake. Counseling to correct improper dietary practices usually follows an evaluation. Follow-up of counseling requires scheduled visits at home or at the clinic with the client-patient. Writing reports and participation in staffing conferences are additional clinical duties. The amount of time spent for each of these specific clinical activities varies considerably from one nutritionist to another. Chief nutritionists spend more time in consultation with agencies or organization, while staff nutritionists are usually relegated to clinical duties.

Training activities have been divided between time spent on teaching formal credit courses and time spent on supervision of trainees in clinical settings. The chief nutritionists spend more time in teaching credit courses and in trainees' supervision than the staff nutritionist. The following credit courses were taught by chief nutritionists:

Child Nutrition
Human Nutrition
Interdisciplinary Approach to Health Care Services
Interdisciplinary Approach to Mental Retardation
Medical Dietetics
Nutrition and Life Cycle
Nutritional Management of Genetically Determined Conditions
Pediatric Nutrition
Readings in Food and Nutrition
Seminar on Mental Retardation
Therapeutic Nutrition in the Community

The chief nutritionists are also currently involved in development of courses such as:

Advanced Rehabilitation Method
Genetics, Nutrition and Mental Retardation
Interdisciplinary Approach to Pubiic Health
Nutrition in Mental Retardation

TABLE 2

Range of Time Spent on a Given Activity

RESPONDENTS	NUMBER OF RESPONDENTS	ACTIVITIES						
		Service		Training				
		Individual	Organization	Credit	Other	Research	Administration	Professional development
		%	%	%	%	%	%	%
All	23	12 - 89	0 - 17	0 - 18	5 - 45	0 - 25	0 - 35	0 - 25
Chief Nutritionists	13	12 - 55	1 - 17	0 - 18	5 - 45	0 - 25	4 - 35	0 - 25
Chief Nutritionists With Staff	6	12 - 50	1 - 17	0 - 13	17 - 45	0 - 25	4 - 35	5 - 21
Staff Nutritionists	10	40 - 89	0 - 10	0 - 15	6 - 20	0 - 10	0 - 30	1 - 20
Full-time Nutritionists	19	12 - 68	0 - 17	0 - 18	5 - 45	0 - 25	0 - 35	0 - 25
Part-time Nutritionists	4	30 - 89	1 - 10	1 - 10	5 - 20	2 - 20	1 - 15	1 - 15

Readings in Nutrition and Abnormal Development
World Nutrition
Nutrition Education and Research

Both chief and staff nutritionists are also involved in giving guest lectures in courses.

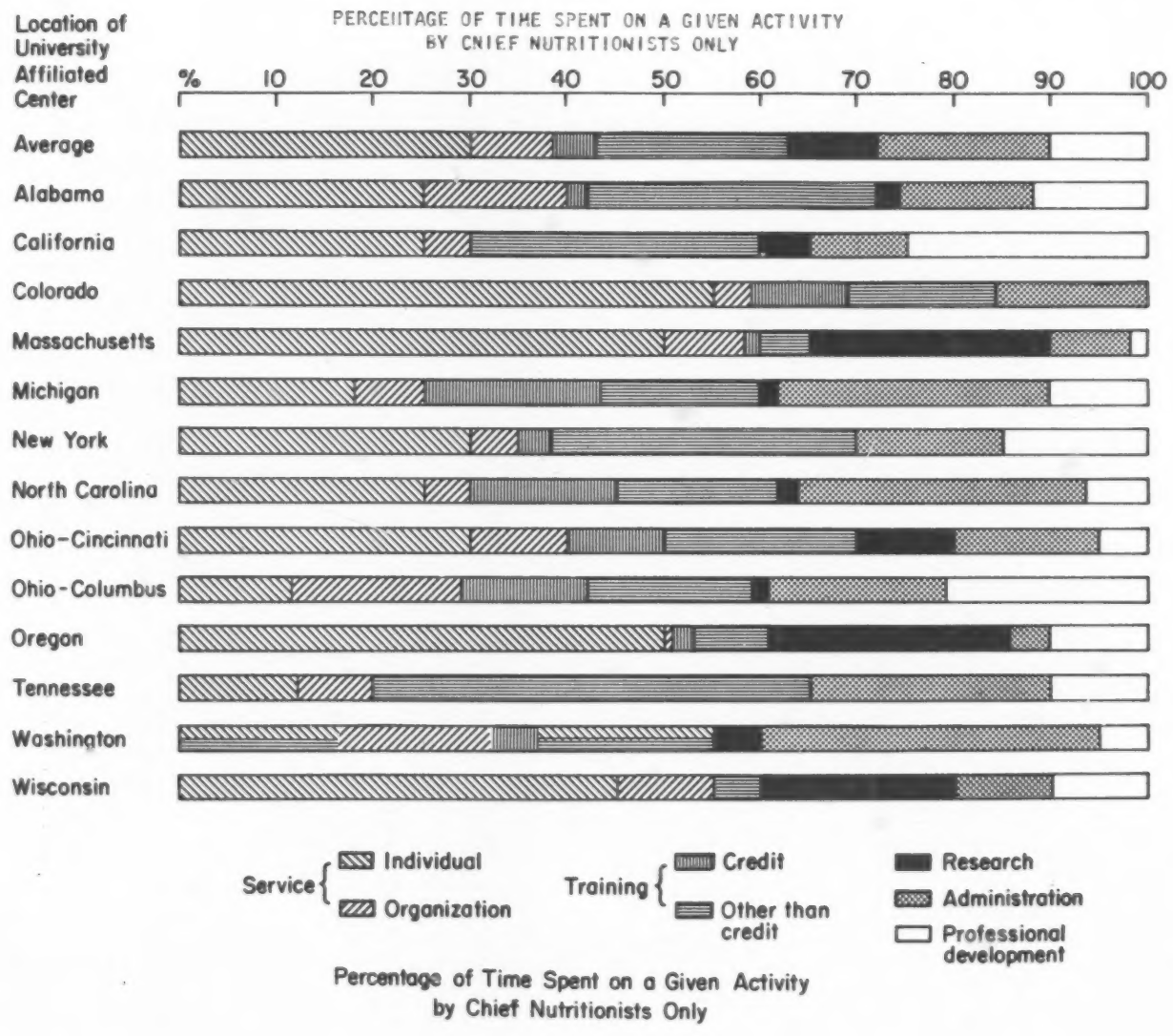
Nutrition students in University Affiliated Centers consist of undergraduates, dietetic interns and g. duate students. Nine University Affiliated Centers offer training programs for dietetic interns, seven for graduate students and five for undergraduate students. University Affiliated Center Nutritionists are also involved in training students from other disciplines. Nine University Affiliated Centers included in this survey have Psychology students, eight have students in Nursing, six in Speech and Social Work respectively, five in Special Education, two in Dentistry, Medicine, Pediatrics, Occupational Therapy, Physical Therapy, respectively, and one each in Psychiatry and Vocational Rehabilitation.

The respondents either spend no time at all or one-fourth of their time in research. The chief nutritionists assume more research responsibilities than the staff nutritionists. Eight of the former are involved in preparation of an article and only four of the latter. Nine respondents, two-thirds of the whole, are chief nutritionists who are involved in some type of research activity. The topics of research are the following:

Amino Acids, Lipid and Sulfatide Disorders
Collection of Data Related to Preschool Children
Dietary History of Children with Myelomeningocele
Interdisciplinary Approach to Obesity
Mechanics of Feeding Handicapped Children
Survey of Phenylketonuria
Review of Literature in Nutrition and Mental Retardation

Administrative activities include membership on committees, development of programs in training, clinical settings and research, and planning of building space and equipment. Full-time nutritionists devote more time to administrative activities than part-time nutritionists. The committees that some of the nutritionists are involved

FIGURE 1



Percentage of Time Spent on a Given Activity
by Chief Nutritionists Only

in are the following:

Administrative Staff
Admission
Clinical Manual
Core Clinic
Curriculum
Executive Supervisors
Film
Grant Obligations
Guidelines
Interdisciplinary Training
Patient Evaluation
Recruitment
Research and Publications
Residential
Trainee Advisory
Training
Treatment

Full-time nutritionists spend more time for professional development than those on part-time. This activity includes reading of professional journals and attending conferences and meetings. Staff development activities provided by University Affiliated Centers are in the form of growth and development seminars, in-service meetings, journal reviews, or staff development meetings.

The percentage of time spent on a given activity, by chief nutritionists only, for the thirteen University Affiliated Centers are given in Figure 1. The average time spent on each of the activities is: 38 percent for service, 26 percent - training, 8 percent - research, 18 percent - administration, and 10 percent - professional development. While the nutritionist at Colorado spends the most time in service to the individual in a clinical setting, the nutritionist in the Ohio State University program spends the least time. This may be accounted for by the fact that at the time of the survey the latter had an additional staff to whom, perhaps, she relegated most of these clinical duties. She spent more time providing consultation services to organizations instead. The center nutritionists in California and in Tennessee do not spend any time at all in teaching credit courses. In the same center the nutritionists spend the most time supervising trainees. Tennessee's center offers short-term nutrition clinical traineeships and fellowships in research. The center at Washington has an equally strong and well developed nutrition program in mental retardation. Besides offering short-term fellowships in nutrition they also offer a Master's degree in Public Health Nutrition with specialization in mental retardation. A little more than one-third of the

chief nutritionist's time is spent on administration. Also, note the overlapping of time spent by the chief nutritionist on supervision of trainees performing clinical service. Chief nutritionists in two centers spend as much as one-fourth of their time on research, whereas three in Colorado, New York and Tennessee did not carry out any type of research. The chief nutritionist in California is new in the field of mental retardation. She, therefore spends as much as one-fourth of her time on professional development, whereas the nutritionist in Colorado indicated in the survey that time spent on professional development is outside her working hours.

As, hopefully, has been seen, the University Affiliated Center nutritionist is indeed a "new breed." The development of University Affiliated Centers has proved the stimulus for broader knowledge, and, therefore, potential for greater understanding of the many problems and considerations the nutritionist must confront. An interdisciplinary setting brings to the nutritionist an awareness of the many-faceted features of her profession. The new breed is not limited to UAC nutritionists nor to nutritionists in general; interdisciplinary training opens for all disciplines as well as all nutritionists similar opportunities for change. Collaboration among the disciplines is essential to the transformation which defines the new breed.

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